

The daily functioning and quality of life of adults with obsessive compulsive disorder: a qualitative inquiry

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ABSTRACT

Obsessive compulsive disorder (OCD) is a highly debilitating psychiatric condition characterized by recurrent intrusive thoughts and images (obsessions) and/or repetitive behaviours aimed at reducing the distress associated with the obsessions. In the absence of treatment, OCD substantially influences the individuals daily functioning (sleep, productivity, leisure, socialising), and quality of life (QOL) (family, friendships and relationships, academics and work, self-esteem). Current literature reports mainly on quantitative findings regarding the influence of OCD on an individual's daily functioning and QOL. Consequently, the lack of in-depth knowledge on the influence of OCD on day-to-day functioning and QOL from the perspectives of patients themselves limits our understanding of this disorder. The present study aimed to qualitatively explore the experiences of adults (18 years and older) diagnosed with OCD within South Africa with a focus on the impact of OCD on their daily functioning and QOL. Twenty individuals with a primary diagnosis of OCD were selected to take part in face-to-face and telephonic semi-structured interviews. All participants gave written informed consent, and were assured of confidentiality and anonymity. Interviews were audio-recorded with the permission of the participants, and transcribed verbatim. Thereafter, the transcripts were entered into a qualitative software programme and thematically analysed. Overall, six main themes and 14 sub-themes were identified, and interpreted through the lens of the Ecological Systems Theory (EST). Thematic analysis unearthed participants' experiences of OCD. More specifically, at the level of the microsystem, awareness of the disorder and its impact on cognitive processes, sleep, daily routine, leisure and socializing was described. At the level of the mesosystem, social support (and absence of support) received from family, friends and colleagues were considered important. Here participants also described the extent to which OCD influences family functioning. At the level of the exosystem, the impact of OCD on work and academic attendance and performance was

salient. At the level of the macrosystem, the use of healthcare services was described. Finally, at the level of the chronosystem participants elaborated on the experience of OCD over time and the use of several strategies that allowed them to cope with, manage and accept their condition. The findings of this study demonstrated that participants experienced poor QOL and functioning in several domains of their lives. These findings are amongst the first to explore OCD qualitatively in a South African sample. Findings may inform practice by providing clinicians with the information necessary to adjust their treatment strategies and to tailor to the needs of the individual. Furthermore, these findings provide clinicians, patients and their families and researchers with a better understanding and greater insight into OCD. Future research should include the perspectives of family members, friends and healthcare professionals in order to capture the impact of the disorder on all those involved.

Keywords: Obsessive compulsive disorder, daily functioning, quality of life.

OPSOMMING

Obsessief-kompulsiewe steuring (OKS) is 'n uitmergelende psigiatriese toestand wat gekenmerk word deur wederkerige en indringende denke en beelde (obsessies) en/of herhalende gedrag wat gemik is daarop om die angs wat saam met die obsessies gaan verminder. Sonder behandeling, affekteer OKS die individu se daaglikse funksionering (slaap, produktiwiteit, ontspanning, sosialisering), en lewenskwaliteit (LK) (gesin, vriendskap en verhoudinge, akademie en werk, self-waarde). Die huidige literatuur weerspieël grotendeels kwantitatiewe bevindinge oor die invloed van OKS op 'n individu se daaglikse funksionering en LK. Daar is gevolglik min in-diepte inligting oor die invloed van OKS op die dag-tot-dag funksionering van LK. Die gebrek aan inligting vanuit die perspektief van die pasiënte self beperk ons begrip van die steuring. Hierdie studie het ten doel gehad om die ervaring van volwassenes (18 jaar en ouer) wat gediagnoseer is met OKS in Suid-Afrika kwalitatief te ondersoek met 'n fokus op die invloed van OKS op hulle daaglikse funksionering en LK. Twintig individue met 'n primêre diagnose van OKS is geselekteer om deel te neem aan een-tot-een en telefoniese semigestruktureerde onderhoude. Alle deelnemers het geskrewe ingeligte toestemming gegee en is verseker van konfidensialiteit en anonimiteit. Onderhoude is met klank opgeneem met die toestemming van die deelnemers en is verbatim getranskribeer. Daarna is die transkripte in 'n kwalitatiewe sagtewareprogram ingelees en tematies geanaliseer. Ses oorhoofse en 14 subtemas is geïdentifiseer. Hierdie temas is deur die lens van die Ekologiese Sisteemteorie (EST) geïnterpreteer. Tematiese analise het die deelnemers se ervaringe van OKS ontgin. Op die vlak van die mikrosisteem het deelnemers bewustheid van die steuring, invloed op kognitiewe prosesse, slaap, daaglikse roetine, ontspanning en sosialisering beskryf. Op die vlak van die mesosisteem het die deelnemers sosiale ondersteuning (en gebrek aan ondersteuning) van die gesin en familie, vriende en kollegas belangrik geag. Deelnemers het as deel van hierdie tema ook die mate waartoe OKS

gesinsfunksionering affekteer, beskryf. Op die vlak van die eksosisteem was die invloed van OKS op werk en akademiese bywoning en prestasie merkbaar. Op die vlak van die makrosisteem het deelnemers die gebruik van gesondheidsdienste beskryf. Laastens het deelnemers op die vlak van die chronosisteem beskryf hoe die ervaring van OKS met die verloop van tyd en met die gebruik van verskeie strategieë verander het sodat hulle dit kan hanteer, bestuur en aanvaar. Die bevindinge van die studie toon dat deelnemers swak LK en funksionering in verskeie lewensdomeine ervaar. Hierdie bevindinge is een van die eerste kwalitatiewe ondersoeke van OKS binne 'n Suid-Afrikaanse steekproef. Die bevindinge kan die praktyk verryk deurdat dit aan klinici die nodige inligting bied om hulle behandelingstrategieë aan te pas by die unieke behoeftes van die individu. Verder bied die bevindinge aan klinici, pasiënte en hulle gesinne 'n beter begrip van en meer insig in OKS. Toekomstige navorsing behoort die perspektiewe van gesinslede, vriende en gesondheidsorgwerkers te ondersoek om die impak van die steuring op almal wat betrokke is te beskryf.

Slutelwoorde: Obsessief-kompulsiewe steuring, daaglikse funksionering, lewenskwaliteit.

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ABBREVIATIONS

CBCL	Child-behaviour Checklist
CBT	Cognitive Behavioural Therapy
DSM	Diagnostic and Statistical Manual of Mental Disorders
EST	Ecological Systems Theory
FAS	Family Accommodation Scale
FOCI	Florida Obsessive Compulsive Inventory
LMI	Low Middle Income
MDD	Major Depressive Disorder
MRC	Medical Research Council of South Africa
OCD	Obsessive Compulsive Disorder
PD	Panic Disorder
PTSD	Posttraumatic Stress Disorder
PDD	Premenstrual Dysphoric Disorder
PI	Principle Investigator
QOL	Quality of Life
Q-LES-Q	Quality of Life Enjoyment and Satisfaction Questionnaire
SDS	Schneier Disability Scale
SDI	Sheehan Disability Inventory
SAS-SR	Social Adjustment Scale Self-Report
SAD	Social Anxiety Disorder (SAD)
SCID-I	Structured Clinical Interview
SU	Stellenbosch University
TA	Thematic Analysis
TTM	Trichotillomania
UCT	University of Cape Town

WHO	World Health Organization
WHODAS	World Health Organization Disability Assessment Schedule
WHOQOL-BREF	World Health Organization Quality of Life measure
Y-BOCS	Yale-Brown Obsessive Compulsive Scale

GLOSSARY OF TERMS

Adult	An individual of 18 years or older.
CBT	Talking therapies that can help you manage your problems by changing the way you think and behave.
Compulsions	Repetitive behaviours aimed at reducing the distress associated with the obsessions.
Daily functioning	Regular activities essential for usual self-care.
FOCI	A 25-item, self-report severity scale.
Heterogeneous disorder	The disorder is caused by multiple mutations, causing different experiences.
Impairment	The state of being weakened, or damaged, especially mentally or physically.
Obsessions	Recurrent intrusive thoughts and images.
OCD	A is a highly debilitating psychiatric condition characterized by recurrent intrusive thoughts and images (obsessions) and/or repetitive behaviours aimed at reducing the distress associated with the obsessions (compulsions).
Quality of life	Individuals' perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns.
Y-BOCS	A 16-item clinician-administered semi-structured interview that is used to assess the severity of OCD symptomatology.

CHAPTER 1

INTRODUCTION

Obsessive-compulsive disorder (OCD) is a highly debilitating psychiatric condition characterized by recurrent and intrusive thoughts and images (obsessions) and/or repetitive behaviours aimed at reducing the distress associated with the obsessions (compulsions) (American Psychiatric Association, 2013). According to the World Health Organization (WHO), OCD is classified as one of the 10 most disabling conditions given its impact on employment and quality of life (QOL) (Veale & Roberts, 2014) and has a lifetime prevalence of 2-3% globally (Fontenelle & Hasler 2008). The prevalence of OCD in South Africa is estimated to be 3-5% (Rosenstein, 2013). OCD appears throughout all stages of development but is diagnosed most commonly during adolescence (Veale & Roberts, 2014). At present, although treatment is available (such as a combination of Cognitive Behavioural Therapy (CBT) and anti-depressants (Stein, 2013)), only about 50% of patients respond to first line treatment (Bystritsky, 2004). Consequently, the treatment for OCD sufferers is often not accessible due to an insufficient number of clinicians trained to deliver treatment services (Sookman, 2015), without which functioning remains impaired.

OCD severely impacts daily functioning and QOL of individuals living with OCD (Dryden-Edwards, 2016). The disorder has a major negative influence on individuals' marital, family, and social relationships, educational and work-related functioning (leading to less functionality/concentration, or even unemployment and lower income), lower socio-economic status, and self-esteem (Hou, Yen, Huang, Wang, & Yeh, 2010; Torres et al., 2006). Functioning and QOL have been investigated at length using quantitative studies. However, these studies do not provide in-depth information regarding patients' subjective experiences of OCD.

1.1 Quality of life and psychopathology

Studies have explored the daily functioning and QOL within several psychiatric disorders including anxiety disorders, personality disorders, and mood disorders (Comer et al., 2011; Korsgaard, Torgersen, Wentzel-Larsen, & Ulberg, 2015; Narud, Mykletun & Dahl, 2005; Piccinni, 2007; Yen et al., 2011). A wide-range of anxiety and mood disorders contribute to major impairment in daily activities and QOL in relation to community norms. In particular, a study focusing on QOL impairments across psychiatric disorders examined impairments in a sample of adults with one of eight anxiety or affective disorders (Rapaport, Clary, Fayyad, & Endicott, 2005). This study made use of a QOL assessment named the Quality of Life Enjoyment and Satisfaction Questionnaire (Q-LES-Q) to assess the degree of satisfaction or enjoyment experienced in relation to participants' everyday functioning, including social relationships and family relations. The results of this study produced scores that were significantly below the community norm and reduced QOL in the following disorders: chronic depression, Major Depressive Disorder (MDD), premenstrual dysphoric disorder (PDD), OCD, dysthymia, social phobia, panic disorder (PD), and Posttraumatic Stress Disorder (PTSD) (Rapaport et al., 2005). However, study findings on the daily activities and QOL in OCD compared to that in other disorders, vary widely. For example, there is some evidence to suggest that OCD patients are worse off than those with schizophrenia (Stengler-Wenzke, Kroll, Riedel-Heller, Matschinger, & Angermeyer, 2007), those with depression (Bobes et al., 2001), and the general population (Alghamdi & Awadalla, 2016; Gururaj, Math, Reddy, & Chandrashekar, 2008; Hertenstein et al., 2013; Srivastava & Bhatia, 2008; Srivastava, Bhatia, Thawani, & Jhanjee, 2011; Stengler-Wenzke, Kroll, Matschinger, & Angermeyer, 2006; Weidle, Jozefiak, Ivarsson, & Thomsen, 2014).

Various studies have shown that the occurrence of psychopathology is associated to negative subjective experiences of QOL (Bobes & González, 1997; Schneier, 1997; Simon,

2003). For example, anxiety disorders are found to weaken QOL by means of the suffering of anxiety itself (and consequently not being able to concentrate and control the anxiety situation), the avoidance behaviour associated with anxiety, and the stigma involved to having emotional difficulties (Schneier, 1997).

1.2 Quality of life and OCD

There is a paucity of qualitative information on the impairments in functioning and QOL due to OCD at the level of the individual and within their immediate environment (Bhattacharya & Singh, 2015; Fennell & Liberato, 2007; Knapton, 2015; Murphy & Perera-Delcourt, 2014; O'Neil, 1999). Indeed, evidence suggests that OCD has a large negative influence on the daily activities and QOL of individuals living with the disorder (Coluccia, Fagiolini, Ferretti, Pozza, & Goracci, 2015). However, there is a discrepancy in the literature as to which domains of QOL (physical: sleep and rest; psychological: self-esteem; level of independence: daily living; social: friendships; environmental: leisure; and spirituality) are most affected and in which ways. For example, amongst an Indian sample of patients ($n = 35$), the psychological and social domains of QOL (as measured on the World Health Organization Quality of Life measure (WHOQOL-BREF)) were more affected than other domains (which also showed impairment) as a result of the internal suffering initiated by obsessions and compulsions (Gururaj et al., 2008). Conversely, other studies found that the psychological and social domains were much less affected, with the environmental domain (i.e. safety, health of physical environment), leisure (daily functioning), and health services etc.) not affected by the condition much (Vasudev, Yallappa, & Saya, 2015). However, evidence from a South African sample of patients discovered impairment in the family functioning domain but not in other QOL domains (Lochner et al., 2003).

Individuals with OCD are likely to display different behaviours, or the same behaviours and experience them differently, for example, some individuals count repetitively,

while the others wash excessively or arrange things in order. Some individuals experience relief from performing compulsions, while others experience anxiety (Abramowitz, Huppert, Cohen, Tolin, & Cahill, 2002; Adams, 2016; Coles, Heimberg, Frost, & Steketee, 2005; Insel, 1990; Langlois, Freeston, & Ladouceur, 2000a; Langlois, Freeston, & Ladouceur, 2000b; Tolin, Abramowitz, Kozak, & Foa, 2001; Van Schalkwyk et al., 2016). A study has shown that patients with OCD had poorer QOL in the following domains: general, psychological, physical, and social relationships. The authors found several factors to have caused the poor QOL such as obsessional symptoms, depression, perceived lack of social support, low social status, combined use of mood stabilizers, and negative effects of medication (Hou et al., 2010). These results showed that patients' QOL was associated with several factors that were specific to them and were influenced by their broader environments such as their interactions with treatment and their social environment. The results therefore showed that different QOL domains were differently affected by OCD. In other words, OCD can be seen as a heterogeneous disorder with different symptom constellations, varying experiences of even very similar symptoms, all influencing the QOL domains in different ways. Therefore, it is important to understand individual accounts of OCD as it may affect rapport between clinicians and patients, case formulation, treatment plans, and treatment compliance. Patients with OCD often also have other psychiatric disorders concurrently or at some time throughout their life. Studies have found comorbid disorders to weaken daily performance and QOL of individuals living with OCD. For example, studies found comorbid anxiety and affective disorders to significantly weaken the daily performance and QOL of individuals living with OCD (Abramowitz, Storch, Keeley, & Cordell, 2007; Fontenelle, et al., 2010). MDD in OCD is also linked with a weakened QOL and a greater functional impairment, because individuals with this comorbidity express more severe obsessions and compulsions

and are more highly impaired in social functioning, emotional well-being and physical health (Besiroglu, Uguz, Saglam, Agargun, Cilli, 2007).

These studies were all based on either self-administered questionnaires, clinician-administered assessments (World Health Organization Disability Assessment Schedule – WHODAS), Family Accommodation Scale (FAS) etc.), or both. There are several sources of bias when using self-report measures, which includes, for example, exaggeration, selective memory, attributions, and telescoping (Alghamdi & Awadalla, 2016). With self-report measures, individuals cannot describe their symptoms in detail. Furthermore, these individuals may be reluctant to admit these symptoms to clinicians for several reasons (such as loss of libido or thoughts of suicide) (Hersen, 2004). A potential limitation to these assessments is that it requires an in-depth understanding of the patient which is not always possible - especially within the research setting (Guy, 1976).

Qualitative research addresses many of these shortcomings and is useful at simplifying and organizing data without complexity and context being destroyed. Qualitative methods can describe in rich detail individuals' personal experiences of phenomena as they are found in different contexts (Atieno, 2009). For example, in 2015, Bhattacharya and Singh conducted four in-depth interviews with individuals living with OCD in India. These interviews sought to understand the individuals' experiences with OCD and the effect thereof on their lives. Their data suggest that individuals living with OCD tend to feel disconnected from others, have difficulty expressing their authentic self, and feel guilty about the onset of their illness (i.e. being responsible for triggering OCD). The data support the notion that OCD severely affects different aspects of QOL such as social functioning (Bhattacharya & Singh, 2015; Coluccia et al., 2015), family functioning and self-esteem. Moreover, it provides additional (more rich) data on the daily functioning and QOL in patients with OCD.

For that reason, more qualitative research is needed to explore these personal differences and experiences which could lead into some insight into the differences observed when assessed quantitatively. Therefore, the purpose of this study was to assess the impact of OCD on the daily functioning and QOL of adults with OCD, using qualitative methods, in order to contribute to the scant qualitative data on the topic.

1.3 Motivation for the present study

Snoek (2000) states that the QOL of individuals is studied mainly for two reasons. First, these studies assess the psychosocial functioning of individuals and recognize particular problems and needs these individuals have at various stages of the disease/disorder process. Second, and more frequently, QOL studies are done to compare the effects of various treatment programmes on the individual's well-being and satisfaction with treatment. By comparing these studies, clinicians may be provided with information on how to maintain or improve clinical decision making.

The extent to which OCD impacts daily living can be assessed comprehensively through in-depth interviews. Quantitatively, it has been shown that OCD affects various domains such as work, leisure, or relationships, but for the purpose of this study, interest was much more on the individual and his/her in-depth experience of OCD in their immediate environment. Therefore, focusing more on the detailed descriptions of participants on how OCD affected various domains in their life, such as leisure, work, or relationships. Notably, there is a lack of qualitative research in understanding the impact of OCD on the QOL of individuals living with OCD. There have been a very few efforts to explore into the subjective component of OCD. Moreover, in South Africa an exploration in this area is still growing. This study addressed these gaps by adding to the scant qualitative data on OCD within a South African context. Furthermore, it is likely that OCD may be experienced differently elsewhere, particularly in rich countries like the USA, because these individuals

have more resources and get specialized treatment (Okpaku, 2014), whereas individuals in Low Middle Income (LMI) countries (such as SA) are poorer and have access to only a few specialists for treatment (Berger, Thomas, Vital, & Wang, 2011; Karodia & Soni, 2015; O'Donnell, 2007; Rosenstein, 2013; Thrush & Hyder, 2014).

This qualitative study formed part of a larger quantitative study entitled: Delineating Endophenotypes of Obsessive-Compulsive Disorder (OCD) and Hair-Pulling Disorder (Trichotillomania [TTM]): An Integrated Pharmacological, Neurocognitive, Genetic and Imaging Study, which was initiated in 2007 in an attempt to generate a better understanding of the cognitive-affective processes in patients with OCD/TTM. This project is still on-going, and is rendering new knowledge on genotype-interaction effects on key brain structures that are involved in OCD/TTM.

1.4 Aims and objectives

The aim of this study was to explore the ways in which OCD impacted on daily functioning and QOL among adults (18 years old or older) living with OCD.

The specific objectives were to:

1. explore the influence of OCD on family functioning;
2. describe the influence of OCD on social activities;
3. discover the influence of OCD on academic performance and work activities;
and to
4. understand the influence of OCD on self-esteem.

1.5 Research question

In this study I sought to understand the everyday functioning and QOL of individuals diagnosed with OCD. The study was guided by one research question in keeping with the objectives:

1. How does OCD impact an individual's daily functioning and QOL?

1.6 Overview of chapters

In Chapter 2 I provide a focused overview of the literature regarding OCD and QOL in relation to the individual's immediate environment, such as family functioning, social activities, academic performance and work activities and self-esteem. The theoretical framework (Bronfenbrenner's Ecological model) within which the study is positioned, is explained here. In Chapter 3, I describe the study's methodology, including the research design, research participants and sampling, recruitment strategy, data collection methods, data analysis method, trustworthiness and reflexivity, and ethical considerations. Chapter 4 includes the study findings and in Chapter 5 I evaluate and interpret the results, including the implications of the results and limitations and suggestions for future practice and research.

CHAPTER 2

LITERATURE REVIEW

OCD can significantly impose on an individual's daily functioning and QOL. Daily functioning may be described as regular activities essential for usual self-care. These activities include everyday movement in and around bed, dressing, eating, bathing, shopping, driving, and leisure (Lawton & Brody, 1969). QOL may be described as an, “individuals’ perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” (World Health Organization [WHO], 1997, p. 1). QOL is further understood as an individual’s satisfaction with health, social, occupational, and other life activities (IsHak et al., 2011; Olatunji, Cisler, & Tolin, 2007). While there is no solid definition of QOL, there is a significant agreement regarding certain characteristics of the notion. QOL is multidimensional in nature as it includes various dimensions such as the physical (the individuals view of their physical state), social (the individuals view of their social roles and interpersonal relationships in their life), and psychological (the individuals view of their cognitive and emotional states) dimensions. Other dimensions of QOL include daily functioning and activities, work, or religion/personal beliefs (Basu, 2004). QOL research has shown that it can provide important information about an individual’s interaction with their illness and their reaction to treatment (Spertus, & Kaufman, 2009), and allows therapists to specifically focus on these aspects (Bystritsky et al., 2001). Often patients learn ways to cope with their condition through these treatment programmes and over time many patients learn to accept their condition (Earle, Eiser, and Grimer, 2005; Hartley, 2007; Lazarus & Folkman, 1984; Tuncay, Musabak, Gok, & Kutlu, 2008). Lazarus and Folkman (1984) identify two types of coping, namely problem-focused coping and emotion-focused coping. Problem-focused coping aims to confront the triggers that cause stress. Subsequently, and by using problem-solving techniques, this

confrontation directly alleviates the stress (Lazarus & Folkman, 1984). Emotion-focused coping aims to confront the negative emotions associated with the stress, such as anxiety or fear. This would include using strategies such as keeping busy, seeking social support, or praying for strength and guidance (Lazarus & Folkman, 1984). In several studies that have explored ways of coping in mental illnesses, patients reported using more emotion-focused coping than problem-focused coping to manage the stressful challenges of their mental disorders, such as Alzheimer's disease and Schizophrenia (Lee & Schepp, 2011; Souza, Chaves, & Caramelli, 2007). However, other studies have found problem-focused coping more successful in medical outcomes (such as diabetes), stressful situations, and depression (Grey, 2000; Hartley, 2007; Turriff, Levy, & Biesecker, 2011). Nevertheless, the obsessions and compulsions associated with OCD can consume a substantial amount of time in an individual's day. Moreover, the irrational and unwanted thoughts and repetitive behaviours affect daily performances associated with family life, social activities, school performance and work success (Chaturvedi, Murdick, & Gartin, 2014; Gluck, 2015; Van Noppen, Boudouvas, Pato, & Rasmussen, 2006). Furthermore, these interactions and activities can be influenced by the environment in which the individual lives, which further influences the individual's development and experience (Cala & Soriano, 2014). This bi-directional influence between the individual and their environment forms part of the Ecological Systems Theory (Bronfenbrenner, 1989), which provides a theoretical basis for this study. These environments consist of four systems, namely, the microsystem (direct relations closest to the individual), mesosystem (interactions between the various microsystems), exosystem (indirect systems), macrosystem (cultural environment), and chronosystem (lifetime transitions) (Bronfenbrenner, 1989).

Since the late 1980s OCD has predominantly been studied using quantitative methods (Goodman et al., 1989; Steketee, Grayson, & Foa, 1985). Very few qualitative studies have

been conducted on OCD. Qualitative studies provide the researcher with an opportunity to elicit rich narratives on the in-depth experiences of a phenomenon from the individuals themselves, with a collective aim of creating new ways of seeing and understanding existing data (Atieno, 2009). Given that the literature is predominantly quantitative in nature, I summarized current quantitative evidence on OCD and QOL and supplemented it with available qualitative studies.

2.1 Literature search strategy

Searches of electronic databases, books, and reference lists were done to identify suitable studies for inclusion. The following online databases were searched: Science Direct, SAGE open, PubMed, Academic Search Premier, PsycArticles and Google Scholar. Online studies were retrieved with the following key words associated with OCD (“obsessive compulsive disorder”, “OCD” “obsessions”, “compulsions”) and was combined by “AND” with key words associated with QOL (“quality of life”, “QOL”, “satisfaction with life”, “functioning”, “social functioning”, “academic performance”, “family functioning”, “self-esteem”). Reference lists of publications were also searched for additional suitable publications.

2.2 Subjective and objective components of QOL

QOL consists of subjective and objective components. To understand the difference between these components, QOL can be explained as the extent to which the objective needs of an individual are fulfilled with regard to the subjective interpretation of their well-being (Constantinescu & Moise, 2011). Therefore, there are two distinctive approaches in the evaluation of QOL: the subjective approach which assesses QOL by means of an individual’s interpretations and actions and the objective approach which assesses QOL by means of economic indicators or material resources (income, housing, food) (Constantinescu & Moise,

2011). More recently, QOL research has focused on exploring subjective feelings of happiness and life fulfilment (Power, Bullinger, & Harper, 1999).

In this study, I followed the subjective approach towards QOL as it reflected the significant experiences of every individual as opposed to the objective approach. The objective approach does not display the actual significance of the well-being experienced by the individuals, as it only focuses on providing liminal values for indicators such as economic, social and material resources. Given the lack of qualitative studies, the subjective approach allowed for participants to explore the extent to which OCD influenced their QOL and daily functioning and/or activities in areas such as family relationships, social, academic and work life, and quality of the sense of self.

2.3 Quality of life and OCD

Evidence suggests that OCD symptom severity is consistently associated with reduced functioning and QOL. For example, various studies have examined the differential effects of obsessions and compulsions on life contentment (Eisen et al., 2006; Foa & Kozak, 1995; Mancebo, 2008; Rodriguez-Salgado et al., 2006; Shakya, 2010; Tanidir et al., 2015). More specifically, studies found that the obsessional symptom severity (rather than the compulsive symptoms) is related to poorer QOL (Eisen et al., 2006; Masellis, Rector, & Richter, 2003), whereas others have shown that compulsive symptom severity was more associated with poorer QOL (Stengler-Wenzke et al., 2007).

Individuals with OCD also show significant functional impairment. For example, studies have shown that these individuals are unable to work effectively and proficiently, complete household responsibilities, or accomplish social responsibilities (Eisen et al., 2006; Hollander, 1997). In a South African study, 14% of a sample of 212 participants had OCD and experienced negative effects such as an interference with social and work activities and a low self-esteem (Stein, Wessels, Zungu-Dirwayi, Berk, & Wilson, 2001). Moreover, through

in-depth interviews, patients in the United Kingdom (N = 9) reported negative influences on their education, work, family and personal relationships (Murphy & Perera-Delcourt, 2014). Other qualitative studies also found OCD to result in poor QOL in the following domains: family, social, academic/work, and self-esteem (Bhattacharya & Singh, 2015; Fennell & Liberato, 2007; Knapton, 2015; O'Neil, 1999). It is clear that OCD substantially impacts on the daily, family, social, academic, and occupational functioning of individuals living with the disorder (Lochner et al. 2003; Stein, Allen, & Bobes, 2000).

An individual's perception regarding their QOL can be evaluated in the following systems, the microsystem, mesosystem, exosystem, and the macrosystem. The ecological systems theory proposes that human development takes place by means of an individual's interaction with the changing environments within which he/she resides and which he or she influences. The individual is influenced by the relationships within and between these contexts, in addition to the larger social settings within which they live (Bronfenbrenner, 1989). Only those domains that were essential to this current study (to the individual's immediate environment) were discussed. These domains include the individual's quality of functioning, family relationships, social, academic and work life, and quality of the sense of self. Several studies have presented that satisfaction in the domains of family, leisure, work, and self-efficacy are positively related to an individual's overall perceived QOL (Bubolz, Eicher, Evers, & Sontag, 1980; Headey, Holmstrom, & Wearing, 1985). According to Way (1990), one can reflect on QOL at a life domains level (such as quality of leisure life, quality of family life, quality of work life) and at an individual level and in addition to the social level.

2.3.1. Quality of functioning

Sleep. Sleep disturbance has been associated with profound adverse consequences for several facets of everyday functioning, including emotional well-being and mood (Haack &

Mullington, 2005). Consequently, reduced emotional well-being and mood are associated with adverse health consequences, reduced physical and mental performance, anti-social behaviour, and increased negative recollections (Blagrove & Akehurst, 2001; Forgas, 1998; Henningsen, Zimmerman, & Sattel, 2003). In severe cases of OCD, individuals' sleep may be disrupted and delayed due to the preoccupation with performing compulsions and obsessive thoughts (Insel et al., 1982; Paterson, Reynolds, Ferguson, & Dawson, 2012; Storch et al., 2007). For example, Coles and Sharkey (2011) reported on an OCD participant who delayed bedtime to complete perfecting complicated sequences of pre-bed routines. This participant also reported on feelings of fatigue due to a delayed bedtime, which resulted in her making mistakes during rituals, and consequently, it caused her to repeat the rituals until she felt they were perfect. However, other studies found insufficient evidence for poor quality of sleep amongst individuals with OCD (Ariaga, Lara, Matos-Pires, Cavaglia, & Bastos, 1995; Hohagen et al., 1994).

Productivity. Research suggests that patients with OCD often show impairment in cognitive abilities, mobility, housework and/or childcare (Koran, Thienemann, & Davenport, 1996; Besiroglu et al., 2007). Cognitive abilities seem to be affected as individuals often report uncertainty as to whether they have performed certain behaviours or merely imagined performing it, thereby increasing the need to repeat behaviours (Hermans, Martens, DeCort, Pieters, & Eelen, 2003; Muller & Roberts, 2005; Tallis, 1997; Van den Hout & Kindt, 2003; Zitterl et al., 2001). Furthermore, recurrent and obsessive thoughts can make it challenging for individuals living with OCD to complete daily activities such as eating, drinking, reading, or shopping, because of constant thoughts such as germs. The time consuming nature of the disorder makes it difficult to complete daily activities. Individuals often view their obsessions and compulsions as irrational and they may feel that they are not able to stop engaging in them (Palermo, 2014), describing their condition as something that consumes their whole life,

and that it is not easy to manage (Mellors, 2006). OCD does not only influence daily activities such as getting things done, eating or shopping, but also functioning in leisure activities.

Leisure activities. Individuals with OCD are often not comfortable with unstructured leisure activities such as holidays. Their leisure activities are likely to be planned. Their hobbies and leisure activities are often taken seriously, by creating these activities into a form of work, triggering symptoms of OCD (Boyd, 2008; Storch et al., 2006). For example, they may turn photography into an opportunity to perfect every single picture taken rather than to enjoy taking pictures. In other words, OCD restricts their ability to relax. OCD not only influences their functioning in daily activities, but also in their family, social, academic and work life, and their self-esteem.

2.3.2. Quality of family life

OCD impacts the lives of both patients and their families (Srivastava & Bhatia, 2008). In a South African study, QOL in patients with OCD, PD, and social anxiety disorder (SAD) were compared using various measurement scales, such as the Sheehan Disability Inventory (SDI) and the Social Adjustment Scale Self-Report (SAS-SR) (Lochner et al., 2003). The authors found that individuals living with OCD had more impairment in family life and daily life activities, compared to the other two groups. The impairment in family life occurred when family relatives became involved in rituals (Amir, Freshman, & Foa, 2000; Calvocoressi et al., 1995; Renshaw, Steketee, & Chambless, 2005; Steketee & Van Noppen, 2004). The impairment in daily life activities occurred across the domains of school, work and home making (Stein et al., 2000). These impairments were found to be consistent with other studies, and these impairments included higher rates of divorce and separation amongst individuals with OCD than amongst those without OCD (Regier, Narrow, & Rae, 1990).

It has been found that an individual with OCD will go to great lengths to ensure that relatives avoid contact with contaminated items (Veale & Willson, 2013). If relatives come into contact with contaminated items, they are required to wash excessively, or required to leave specific clothes or shoes outdoors. It has been further stated that these individuals may want their relatives to check that doors are locked frequently, or may persistently be searching for verification that nothing harmful has occurred (Veale & Willson, 2013).

Furthermore, it has been suggested, by means of clinical observations, that relatives of patients with OCD are engaged in the patients' rituals, often weakening or damaging their own daily lives. Contrasted with that of the general population, the QOL of these family members, when evaluated on WHOQOL-BREF, was considerably lower in the areas of social, physical, and psychological well-being (Srivastava & Bhatia, 2008).

Moreover, another study found that OCD instils persistent worry, increases responsibility of care, and creates distress among family members at their restricted ability to support the individual (Abbey, Cloptom, & Humphreys, 2007; Perez, 2008; Piacentini & Langley, 2004; Shafran, Ralph, & Tallis, 1995; Stengler-Wenzke, Trosbach, Dietrich, & Angermeyer, 2004; Subramaniam, Abdin, Vaingankar, & Chong, 2012). However, through in-depth interviews with individuals living with OCD in India, it was found that some individuals experienced a disconnection and lack of emotional support from their family, because of their condition (Bhattacharya & Singh (2015). Moreover, in Spragg's study, a South African participant reported keeping her condition of OCD a secret from both her mother and husband because of their unfriendliness and negative responses to her difficulties (Spragg, 2013). Consistent with other studies, this participant reported feeling unacceptable when performing rituals in the company of her family, creating feelings of shame (Besiroglu & Agargun, 2006; Spragg, 2013). It has, however, been argued that the involvement of the family is often supportive and positive and provides the necessary support to reduce distress

for the individuals and their family (Maina, Saracco, & Albert, 2006). Conversely, the National Collaborating Centre for Mental Health (UK) (2006) states that, over time, this sort of involvement may become unsupportive and unhelpful. Other studies have also found this to be the case (Albert, Salvi, Saracco, Bogetto, & Maina, 2007). It is clear that OCD may have a profound influence on the family and weaken family functioning in quite a few areas of family dynamics. Helping an individual with their rituals can maintain OCD and therefore create difficulty in the individual's recovery. However, when family relatives are more knowledgeable about OCD, it can be easier to be understanding and supportive.

Evidently, more in-depth information from the individual regarding family functioning has not been collected. This study hoped to fill this gap by exploring the QOL in OCD patients through in-depth interviews, focusing on questions related to the family's experiences of the individuals diagnoses of OCD. This provided an effective means of interpreting the extent and context of the weakening of family functioning, which is likely to contribute to interventions and treatment.

2.3.3. Quality of social life

Evidence suggests that OCD can negatively influence social functioning and activities, as individuals are likely to experience a reduction in social activities and loss of friendships (Steketee, 1997). Since these individuals (particularly those with compulsions) are often preoccupied by their obsessions and/or compulsions, their social lives become restricted (French, Mary's Harbour, & Nesbit, 2009; Langley, Bergman, McCracken, & Piacentini, 2004; Stengler-Wenzke et al., 2007). In a previous study that assessed the effects of OCD on family, school, and social functioning, it was found that social functioning was less prevalent than functioning in the home, family and academic domains (Piacentini, Bergman, Keller, & McCracken, 2003).

However, in a South African study, the dissimilarities in functional impairment amongst South African children diagnosed with OCD were studied (Fischer, 2009). In this study, the Child-Behaviour Checklist (CBCL) and the Schneier Disability Scale (SDS) were used. The results show that children and adolescents with OCD reported most difficulty in social functioning and impairment in the friendships and daily activities' domain (Fischer, 2009). The consequences of OCD can affect the individual's social functioning- such as withdrawal from normal activities and interaction with friends (Van Noppen et al., 2006).

The explanations for social deficits are said to be multi-causal and may show that the overprotection from parents or regular hospital stays delay the development of permanent relationships (Moritz, Niemeyer, Hottenrott, Schilling, & Spitzer, 2013). However, it is possible that this could result in social avoidance, which could later lead to the view that others should not be trusted. As a result, it is likely that individuals with OCD experience shame and embarrassment, increasing isolation and reducing social relationships. On the other hand, individuals may also feel ashamed because they view their symptoms as irrational. These individuals eventually become aware of their abnormal behaviour, but lack recognition for it, which builds a sense of fear that others may view them as irrational and this makes them secretive about their condition (Chen, 2002; Goodwin, Koenen, Hellman, Guardino, & Struening, 2002; Gulliver, Griffiths, & Christensen, 2010; Hyman, 2008; Jorm, 2000; Jorm, 2011; Kessler et al., 2001; Singh, 2002; Vogel & Wester, 2003; Welfare, 1993).

Evidence on lived experiences of OCD was expressed by explanations of psychological distress when attempting to form friendships, leading to avoidance and feelings of isolation (Bhattacharya & Singh, 2015; Helbing & Ficca, 2009; Murphy & Perera-Delcourt, 2014). For example, in Bhattacharya and Singh (2015) and Murphy and Perera-Delcourt (2014), participants reported feeling uncertain and angry with how their friends treated them, because of a lack of understanding of their condition, which lead to them

distancing themselves from their friends. It is not only OCD that affects the individual's social interaction; it is also affected by a lack of social support. In a study by Hou, Yen, Huang, Wang, and Yeh (2010), the authors examined the links between QOL and sociodemographic information, course of the disorder, psychopathology, perceived social support and types of treatments. As a result of the study by Hou et al. (2010), poor QOL in terms of social relationships was associated with low social support in patients with OCD. Furthermore, the authors found that poor QOL with regard to social relationships were associated with low social statuses. It has, however, been argued that since OCD has a negative influence on the ability to work and financial independence, the social status of individuals living with OCD can weaken during the progression of the illness, causing poor QOL (Hollander, 1997; Stein, Roberts, Hollander, Rowland, & Serebro, 1996). It is obvious that OCD can create difficulties to participating in activities and maintaining social life. Some individuals may experience fear of displaying rituals in public, fear of being judged by others, and the fear of humiliation, which is likely to cause these individuals to avoid such activities and situations. Increasing the amount of social support is likely to assist in reducing the feelings of burden. What remain unclear are the individual's judgments about their relationships and social activities such as perceived quality of their relationships and social activities. This study aimed to address this gap through in-depth questions regarding participants' social relationships and activities.

2.3.4. The quality of academics and work life

Individuals that struggle with OCD are often seen as highly operative, skilled individuals who would rather keep their disorder a secret and attempt to deal with it (Cohen-Posey, 2010; Long, 2015). On the other hand, they tend to keep their condition a secret, because a fear of showing an unacceptable characteristic of their personality (Corrigan, 2004; Ferrier & Brewin, 2005; Newth & Rachman, 2001; Rachman, 1997; Schomerus &

Angermeyer, 2008). These individuals may experience anxiety, lack of concentration, poor attention span, slow performance, and difficulties associated with poor functioning in academics (Neal-Barnett & Mendelson, 2003; Paige, 2007). They may appear distracted and lacking in the ability to focus. The rituals individuals participate in could influence their attendance at work. By these individuals concentrating on the distressing compulsions and/or thoughts, they may avoid situations that intensify their compulsive and/or obsessive thoughts. As a result, they may fail to attend to learning time, or to their daily jobs (Paige, 2007; Tompkins, 2012). For example, OCD can affect an individual's academic or work performance if the individual is constantly reading and rereading sentences, paragraphs, articles, or pages in a book while working. Consequently, there is less time to learn and work successfully, as an ample amount of time is occupied by rituals (Adams, 2004; French et al., 2009; Purcell, 1999; Rees, 1997). If OCD is left untreated, it is likely for individuals to experience adverse effects on their learning and careers, such as poor grades and decreased work production. Therefore, the influence OCD has on academics and work performance should not be underestimated as it can impose difficulties on an individual's ability to read and focus, such as being distracted from the thoughts or need to complete rituals. In the study by Angst et al., (2004) psychological well-being and QOL at work were the domains mostly suffered by participants. Supporting this is a South African study which studied the functional impairment in children and adolescents with OCD (Hoppe, 2009). This study also found participants to have experienced impairment in the academic/work domains. Relating to this, individuals with OCD have less academic successes, higher unemployment rates, depend more on social security for allowances, and they have a lower average income (Rodriguez-Salgado et al., 2006).

Since individuals living with OCD often have difficulty in working, it has been stated that these individuals are more prone to be unemployed. Their obsessions and compulsions

often occur at work, placing undue strain on them and exhausting them (Hart & Björgvinsson, 2008; Hauschildt, Jelinek, Randjbar, Hottenrott & Moritz, 2010; Veale & Willson, 2013). However, there is a discrepancy in the literature regarding unemployment vs. employment amongst individuals with OCD. In another study that studied the long-term effects of OCD, a few participants older than 16 years who received treatment for OCD, reported that they were employed. Only two participants reported difficulty in sustaining a job (Hollingsworth, Tanguay, Grossman, & Pabst, 1980). Additionally, through in-depth interviews participants reported their experience of OCD as a chronic issue. However, many of them were still functioning in society, such as having a job (Fennell & Liberato, 2007). It is clear that individuals who have untreated OCD are likely to experience difficulty with concentration in their academics and work. A major gap in this domain is the lack of in-depth information about how individuals experience their condition during varsity or work, and how that experience makes them feel. This study addressed this gap by asking questions regarding the individual's experience of how OCD impacted their academic performance and work activities. This provided strong qualitative data by looking at an individual's judgment of the capability of their academics or work situations while living with OCD.

2.3.5. Quality of the sense of self

It has been stated that individuals with compulsions (checking) are compelled by an inner drive to arrange things perfectly and feel accountable for their failure to succeed in perfectionism, and as a result it decreases self-esteem and increases feelings of guilt (Aardema & O'Connor, 2007; Mancini, Gangemi, Perdighe, & Marini, 2007; Shafran, Watkins, & Charman, 1996). In another study, a negative correlation was also reported between self-esteem and the severity of OCD, and a positive correlation between OCD and guilt (Ghafoor & Mohsin, 2013). Through in-depth interviews, participants reported that their thoughts about unacceptable thoughts or having compulsions lead to feelings of guilt and to

overcome this guilt they have thoughts of an inauthentic life (Bhattacharya & Singh, 2015). Consistent with other studies, these individuals felt hopeless and powerless as a result, because they could not live up to particular expectations- consequently decreasing their self-esteem (Bhattacharya & Singh, 2015; Carroll, Pantelis, & Harvey, 2004; Crisp, Gelder, Goddard, & Melther, 2005; Wahl, 1999). According to McClure (2014) and Bandura and Wood (1989), individuals may feel trapped and anxious when they cannot control the things that make them feel hopeless, therefore having little belief in their ability to succeed. On the other hand, self-esteem is commonly measured by scales, subsequently lacking in-depth information on how patients with OCD value themselves. This study addressed this by asking questions regarding how participants felt about their condition and how this influenced their self-esteem.

2.3.6. Conclusion

In summary, numerous quantitative studies proposed that the daily functioning and QOL of individuals with OCD are significantly poorer than that of the general population (Koran et al., 1996; Rapaport, Clary, Fayyad, & Endicott, 2005). In qualitative studies, patients described themselves as being overwhelmed by personal failure as it negatively influenced their daily activities, education, occupations, family and personal relationships (Murphy & Perera-Delcourt, 2014). OCD seems to influence the way individuals feel about their disorder, since individuals describe it as taking over their whole life, and that it is not easy to cope with. The way individuals feel about their disorder can influence their interactions with the various environments within which they live, and in turn these environments can influence their experience of the disorder. Living with OCD makes it challenging for individuals to complete daily activities such as sleeping, eating, drinking, reading, shopping, or leisure, as it consumes so much time and effort, not allowing for these activities to be completed. OCD also seems to impact the lives of both patients and their

families, as relatives of these individuals engage in the individual's rituals, causing distress in their own lives. It also affects an individual's social functioning, as they are likely to avoid and isolate themselves from the psychological distress caused when attempting to form friendships. Furthermore, OCD influences academic performance and work activities, not allowing them to focus, make decisions, or complete tasks, as a result of their being distracted from their thoughts or need to complete rituals (Rocha, Alvarenga, Malloy-Diniz, & Corrê, 2011). These individuals may experience shame and embarrassment, making them feel hopeless, and as a result decreasing their self-esteem.

Most of the available qualitative studies have reported mainly on the construction of self of individuals living with OCD (Fennel & Liberato, 2007; Knapton, 2015; O'Neil, 1999). To address this caveat, the current study explored the impact of this condition on their daily functioning and QOL, particularly amongst individuals in South Africa. This study intended to better understand significant issues that arise when a person develops this condition, across domains of daily activities, family, social, and academic and work life, and self-esteem.

Several of the existing qualitative studies (Fennell & Liberato, 2007; Knapton, 2015; Murphy & Perera-Delcourt, 2014) emanate from resource-rich countries rather than LMI countries like South Africa. The present study addressed this gap.

2.4 Theoretical Framework

Ecological Systems Theory (EST), as laid out by Bronfenbrenner (1979), informed the planning, procedures and findings of this study. It was used in this study in an attempt to explain the influence that OCD had on the daily functioning and QOL of individuals diagnosed with OCD.

EST is comprised of five fixed environmental systems (see Figure 1) that influence an individual's development. The EST represents different levels of environmental influences

that affect and link with an individual's emotions, behaviour, and functioning as a whole (Okun, 2005).

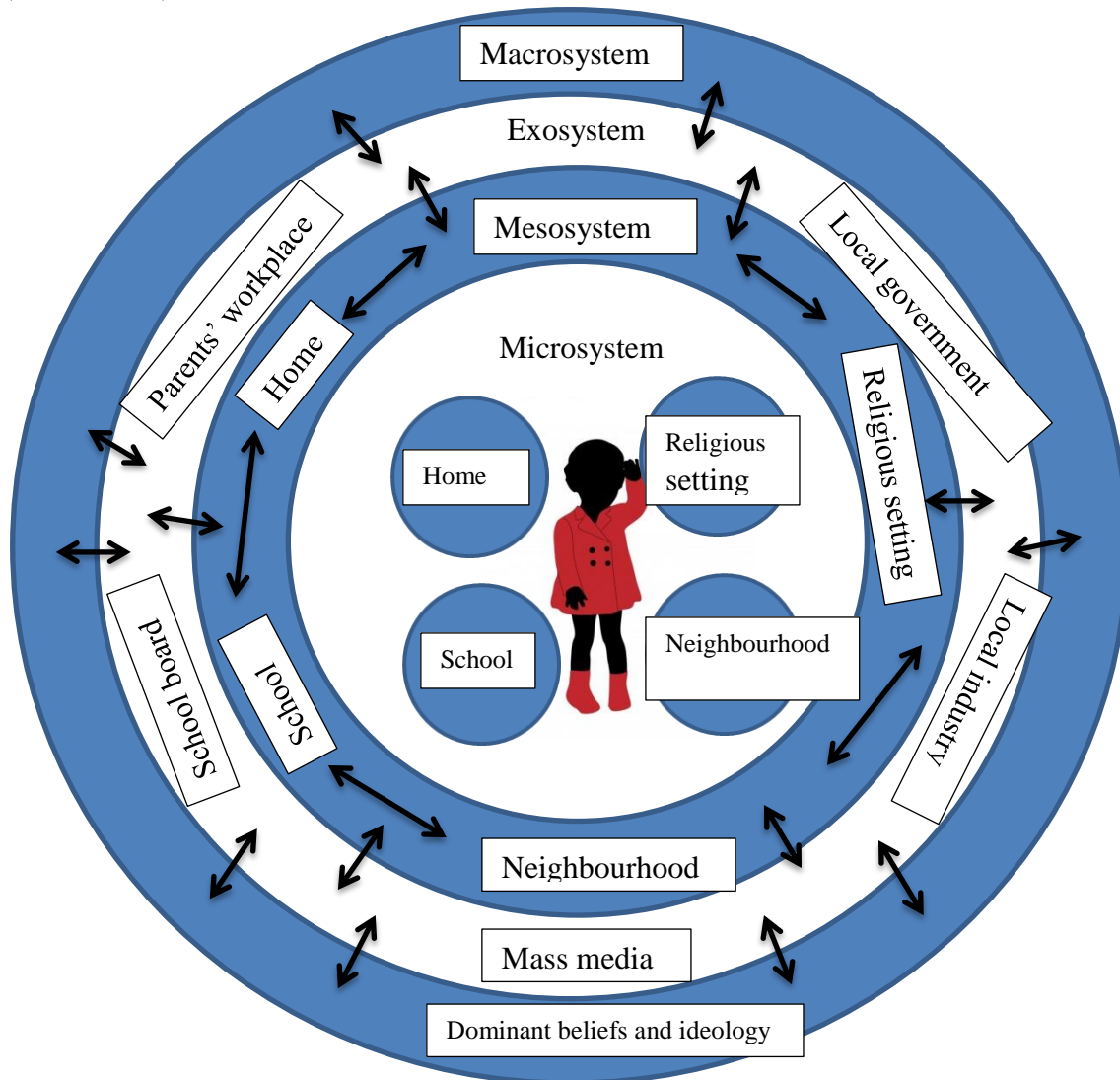


Figure 1. The five systems of Bronfenbrenner Ecological Systems Theory adapted from Härkönen (2007).

These systems include 1) microsystem- the direct contact individuals have with activities, social and interpersonal relationships on a daily basis such as family; 2) mesosystem- refers to the link between two or more microsystems surrounding the individual such as the relationship between the individual's family and workplace; 3) exosystem- the link between two or more systems with whom the individual has indirect interaction with, but has an effect on the individual such as workplace policies; 4) the macrosystem- the social

factors that affect the individual's life, such as the individual's ideology, and 5) the chronosystem- events that occur in an individual's life (Bronfenbrenner, 1989; Visser, 2007). All these systems are connected to one another in a bi-directional way.

The influence of OCD on an individual's daily life could be influenced by any system with which the individual interacts. Therefore, one can explain how the different systems influence individuals' experiences of living with OCD.

Microsystem. In the microsystem and in relation to QOL in OCD, factors directly related to the individual, such as unwanted thoughts and compulsions that influence them and their daily activities, are considered. Furthermore, the individual's contact with members in his/her direct environment such as family or spouse is also considered. For example, family support is fundamental to the emotional development of children (Howe, Brandon, Hinings, & Schofield, 1999). It has been found that adolescents who are content with their family share more emotional information with their parents, are more accommodating with family expectations, and primarily, have a greater QOL (Henry, 1994). Henry (1994) attempted to further explore the factors related to an individual's satisfaction with family life as a way to improve the individual's well-being. This was assessed by the use of various measurements. For example, the individual's satisfaction with family life was assessed using the Adolescent Family Life Satisfaction Index and a 4-item subscale to assess the extent to which individuals saw each parent as providing support (Henry, 1994). Therefore, one can assume that support can improve self-esteem, which may reduce negative life experiences of OCD. However, if these individuals are not supported, they could experience a poorer QOL.

Mesosystem. In the mesosystem, different environments can have different influences on one another, subsequently influencing the individual. It has been argued that there is a complex relationship between emotional, social and academic development (Raver, 2002). For example, being emotionally supported can influence social interactions positively, which

in succession can influence school performance. Therefore, if an individual living with OCD is not emotionally supported by family, it can adversely influence their performance at work. Consequently, this can adversely influence how their managers, colleagues and friends relate with them. Subsequently, this results in a poor cycle of emotional support for the individual living with OCD. It is important to note that emotional support in an individual's development is extremely important as individuals need to interact with others.

Exosystem. Within the exosystem, various systems can indirectly influence the individual, such as workplace policies. This example reflects an indirect influence of a workplace policy on an individual with OCD looking for employment. If workplace policies include exclusion criteria of mental disorders, the individual living with OCD would struggle to find employment, which could then influence their finances to pay for treatments.

Macrosystem. This system can relate to the cultural context of the individual. An individual may believe in certain things, because he/she belongs to a specific ideological community. For example, an individual with OCD and his/her community may believe in only natural remedies to treat disorders. The community may therefore not provide the necessary treatment or the individual might not seek treatment, compounding the disorder.

Chronosystem. The EST attempts to provide an explanation for the development of the individual in the context of the environment in which he/she is situated. Therefore, an individual's development throughout his/her lifetime is greatly shaped by environmental influences and the many relations he/she comes across in his/her environment. The chronosystem includes environmental events (natural disasters), transitions over the course of life (death of a relative), and socially historical events (Yingst, 2011). This theory was appropriate for this study, as it tried to research and discover the relationship particularly between the individual with OCD and his/her immediate environment.

2.5 Conclusion to chapter

There are several environments that play a role in how the individual develops and experiences their OCD. These environments include domains such as quality of functioning, quality of family, social, academic and work life, and quality of sense of self. The individual interacts with these environments and is influenced by the relationships within and between these environments. Research on daily functioning and QOL in OCD is mostly derived from quantitative research. We therefore lack an in-depth understanding of how individuals actually experience their condition across these various environments. The present study therefore aimed to attend to this gap. In Chapter 3, I discussed the methodology that was used to conduct this study.

CHAPTER 3

METHODS

3.1. Research design

To attend to the research objectives, an exploratory qualitative research design was applied, guided by a phenomenological approach. Qualitative research focuses on meaning-making as it generates a rich description that inform a reader as to the important structures essential to the actual human experience (Thorne, 2000). According to Silverman (2013), qualitative research uses natural data to find the categories ('how') in which participants' meanings ('what') are used. Interviewing provides an opportunity to gather and carefully analyse narrative explanations of social worlds (Miller & Glassner, 2004). Qualitative research is well-suited to this study as it sought to document individual narratives and experiences.

In this research study, I gathered data from individuals with a primary diagnosis of OCD. OCD was diagnosed according to the DSM-IV-TR (see Appendix A), which includes the following diagnostic criteria: 1) there is a presence of obsessions and/or compulsions, 2) sometime in the course of the disorder, the person has realized that the obsessions or compulsions are unreasonable or excessive, 3) these obsessions or compulsions are time consuming, or significantly impede with the person's standard routine, social, occupational or academic functioning, 4) if another Axis I disorder is present, the content of the obsessions or compulsions is not limited to it (for example, hair pulling in the presence of Trichotillomania), and 5) the disorder is not a result of the direct physiological outcomes of substances or a general medical condition (American Psychiatric Association, 2000).

3.2. Recruitment strategy

Participants were informed about this study through an email drafted by the PI (CL) of the larger study, prior to being contacted by me. Once this was done, I contacted the participants either telephonically or through e-mail and invited them to participate.

3.3. Research participants and sampling

This study was conducted at the SU/UCT MRC Unit on Anxiety and Stress Disorders –which is situated in the Department of Psychiatry of SU. Participants were selected from an existing database (HREC ref no: M07/05/019) and were previously diagnosed with OCD by the study PI (CL), using the Structured Clinical Interview for the DSM (SCID-I) and the SCID-OCD. Given that the contact information for possible participants was already available to the PI, these participants were selected through convenience sampling. Convenience sampling takes all accessible individuals up until the sample attains the preferred size (Bless, Higson-Smith, & Sithole, 2013). Sixty participants were invited to participate, 23 of whom had initially agreed to be interviewed. Of the 23 who showed an interest in taking part, only 22 responded after follow up and only 20 were interviewed. The participants that were not interviewed by me were not contactable (contact details changed or there was no response), were out of the country or no longer resided in the Western Cape, did not have clinically significant OCD at the time of receiving the invitation from CL, and were not interested or could not take time out due to work obligations. Data collection stopped at 20 participants, given that no more new information was being elicited during the interviews (Fusch & Ness, 2015; Mason, 2010).

3.4. Data collection methods

Interviews were conducted at the convenience of participants and took place at either the MRC unit, Stellenbosch University or at participants' homes. Before the interview was done, I informed participants about the purpose of my study and that their participation was

entirely voluntary. I also asked for participants' permission to be audio recorded during the interviews. Participants who were included gave informed consent and remained anonymous. Participants completed a demographic questionnaire and a self-report OCD severity measure—the Florida Obsessive-Compulsive Inventory (FOCI) before the start of the interview (Appendix B). Additionally, an objective, clinician-administered scale, the Yale-Brown Obsessive Compulsive Scale (Y-BOCS) was also used to assess OCD severity. These two severity scales (FOCI and Y-BOCS) were included to provide me with a better understanding of the clinical profile of the participants.

Demographic questionnaire (Appendix B). The demographic questionnaire assessed demographic information such as age, first language, gender, marital status, current living situation, education level, work situation, annual family income, onset of obsessive-compulsive symptoms and the onset of the disorder, and current use of medication. This background information was used to get to know the participants and to make interview questions more specific.

FOCI (Appendix B). The FOCI is a 5-item, self-report severity scale. The number of severity ranged from 0-4 (of which higher scores point to greater symptom severity). Participants endorsed symptom(s) on the severity scale across five areas: 1) On average, how much time is occupied by these symptoms? 2) How much distress do they cause you? 3) How hard is it for you to control them? 4) How much do they cause you to avoid doing anything, going anyplace, or being with someone? and 5) How much do they interfere with school, work, or your social or family life? These items were added up to provide a total severity score, which can be found in Table 1.

Y-BOCS. The Y-BOCS is a clinician-administered semi-structured interview that is used to assess the severity of OCD symptomatology. This scale contains 16 items that is scored on a five-point Likert scale, which ranges from 0–4 (of which higher scores point to

greater disturbance). This scale consists of three sections, items 1–5 represent disturbances associated with obsessions, items 6–10 represent compulsive related disturbances, and the remaining items 11-16 represent questions about both obsessions and compulsions. However, items 11-16 were not included in the total severity score, because they were introduced for exploratory purposes and therefore seen as investigational items. The first 10 items were added up to provide a total severity score, which can be found in Table 1.

The interview process. The interviews lasted 53 minutes (range: 31 to 108 minutes) on average. Interviews were arranged telephonically and took place at the participant's earliest convenience. Participants, who were unable to meet face to face, were interviewed telephonically or via Skype. Interviews were conducted in either English or Afrikaans, using a semi-structured interview schedule (see Appendix C and D). Semi-structured interviews are flexible tools, as participants are provided the opportunity to communicate freely and openly, and to explore their own understanding of what is being said in the interview. This type of interview allows the researcher to request further clarifications which enhances the credibility and trustworthiness of the data (Bryman, 2012). Other methods were also used to ensure the rigour of the data, such as member checking, interviewer examination and debriefing, and detailed descriptions of the methods used in this study. These methods are further discussed in the trustworthiness and reflexivity section. English interviews were conducted by me and Afrikaans interviews were conducted by an Afrikaans speaking master's student in the department. I was also present during the Afrikaans interviews.

During the interview, participants were encouraged to talk openly. However, several factors influenced the duration of the interviews. In instances where participants became emotional during the interview-the interviews were stopped for a period of time, and only continued on the basis that the participant was comfortable with doing so. Participants who became emotionally distressed during the interviews were referred to CL if they so requested.

Older participants (ages 52-69) were often unable to articulate the past due to an inability to remember or to concentrate for prolonged periods of time. In an attempt to steer the narrative back on topic, several probing techniques were used to capture necessary information. Some participants were noticeably anxious (such as struggling to discuss experiences due to nervousness) and in this way I was given some insight into their experiences of anxiety provoking situations. No more than two participants were scheduled on a given day (except once when I had seen four on one day as these interviews took place in Worcester) in order to be fully attentive during each interview.

3.5.Data analysis

The data collected from the interviews were analysed using ATLAS.ti v 7, a computer assisted qualitative data analysis tool that assists researchers with coding and collating of qualitative data. The interviews were digitally recorded and transcribed verbatim. The interview transcripts were thematically analysed (TA) according to the procedures outlined by Braun and Clarke (2006). As such, the analysis followed a six phase approach to data analysis (Braun & Clarke, 2006).

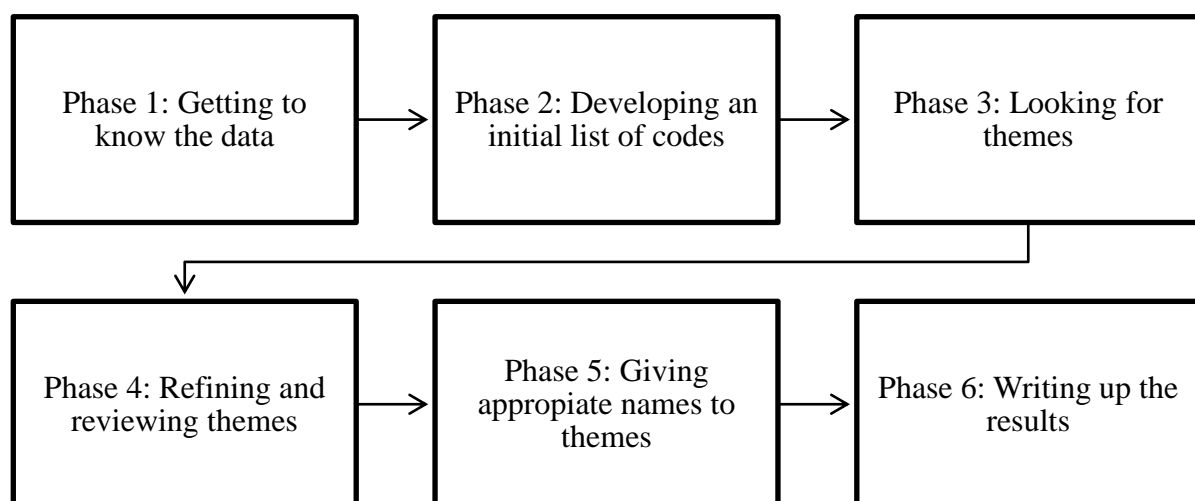


Figure 2. Six phases of thematic analysis, adapted from Braun and Clarke (2006) as used within ATLAS.ti v7

Phase 1. This phase entailed a close reading of the transcripts, numerous times. During the transcription of interviews, I encountered some difficulty with transcribing the Afrikaans interviews. At times, some participants spoke too fast and it was difficult to accurately transcribe their responses. However, I made notes during these interviews and where it was difficult to transcribe, I listened to the recording several times and returned to the notes made in order to make sense of what had been said. Once all the interviews were transcribed, I read through the transcriptions and became familiar with the content of the interviews. I made notes of any thoughts, reflections, or patterns found throughout the data (Willig, 2008). During this phase I also kept a record of potential codes to use during the formal coding phase. Data coding was done independently by me. My supervisor (BC) listened to a sample of the interviews, analysed them and provided quotes as evidence of the interpretations she made from the data, which I had agreed on. This was done in order to improve rigour by cross-checking the data between my main supervisor and myself.

Phase 2. During this phase, I reviewed initial codes for redundancy. Codes with inter-related meanings or ideas were merged into a single code.

Phase 3. During this phase, I refocused codes into themes. Each cluster of codes represented a potential theme and associated sub-themes. As Braun and Clarke (2006) explain, “A theme captures something important about the data in relation to the research question, and represents some level of patterned response or meaning within the data set” (Braun & Clarke, 2006, p. 10).

Phase 4. In this phase I searched for links between emerging themes, clustered them together in line with conceptual similarities, and decided which themes were definite and contained enough data to support them (Braun & Clarke, 2006). The network view function in ATLAS.ti provided a visual space within which decisions about themes could be made. In

the network view, quotations pertaining to a theme were re-read and used to decide whether they adequately captured the essence of the theme to which they were coupled.

Phase 5. This phase entailed refining, defining, and assigning descriptive labels to each theme (Braun & Clarke, 2006). At this stage another level of refinement was used based on theory (Ecological System Theory, Bronfenbrenner, 1979) and data. During phases 4 and 5, I used memo writing to reflect on the content of the themes and to synthesize the overall meaning pertaining to the theme. Memos developed in ATLAS.ti were attached to the relevant networks.

Phase 6. In this phase I presented the results of the data analysis.

3.6. Trustworthiness and reflexivity

The importance of trustworthiness in research is highlighted by Williams and Morrow (2009). According to these authors, trustworthiness is achieved through the balance between reflection, subjectivity, and a clear report of the findings. Trustworthiness can be evaluated across four categories: credibility, transferability, dependability, and confirmability (Guba & Lincoln, 1985).

Credibility. The concept of credibility refers to whether there is a similarity in the way the participants understand the social constructs and the way the researcher interprets their perspectives (Mertens, 1998). I used the following methods to ensure credibility in this study: member checking, interviewer examination and debriefing, and triangulation.

Member checking. During the interview process, member checks were done to ensure that the information provided by the participants were drawn and reported correctly according to their reality and stories. I constantly summarized the responses of the participants together with my own interpretation during the interview to ensure that my understanding of their responses was correct. Where interpretation appeared to be incorrect, participants were able

to correct me. Most participants approved my interpretations and provided further detail on the interpretations during the interview.

Interviewer examination and debriefing. After Afrikaans interviews were conducted, discussions took place with the interviewer of those interviews to check consistency of interpretations.

Triangulation. Triangulation is method of cross checking and validating data by using two or more investigators (Mertens, 1998). As previously mentioned, this was done through cross-checking the data between my supervisor (BC) and myself. Overall, every attempt was made to provide an accurate account of participants' narratives.

Transferability. The concept of transferability refers to the degree to which the data or results of a study can be generalized or transferred to other settings, interests, and contexts (Guba & Lincoln, 1985). In this study, I did not attempt to generalize the findings. I merely attempted to find what is significant for individuals with OCD in SA. While it is not possible to generalize these findings, they could be transferrable to other, similar LMI settings. I aimed to provide a thick description of the research findings. These findings are likely to benefit others experiencing similar situations.

Dependability. The concept of dependability refers to the reliability of the results attained from the data and whether the study can be repeated (Guba & Lincoln, 1985). To ensure dependability, I provided detailed descriptions of the research design, research participants and sampling, recruitment strategy, data collection methods, and data analysis.

Confirmability. The concept of confirmability refers to the researcher's knowledge of bias in research and ensuring that the data are accurate and not simply a creation of the researcher's imagination, (Mertens, 1998). In other words, the researcher must ensure that the findings are true representations of the participants' realities (Guba & Lincol, 1985). This can be attained through rich descriptions and reports of results by using direct quotes to confirm

interpretations and as evidence for interpretations, analysis of theory and practice and presenting a relationship between findings of the research and the literature (Williams & Marrow, 2009). I have tried to attain this with evidence of my interpretations by means of embedding relevant quotes into research results. I have also attempted to relate the research findings with current literature and theories.

Reflexivity. The concept of reflexivity refers to the amount of influence the researcher applies, either intentionally or unintentionally, on the results (Jootun, McGhee, & Marland, 2009). This concept provides some sight into how the researcher made sense of the research process and how that could have affected the research process. Given that I was the leading instrument in this study, it was expected that results may have a subjective association. Every attempt was made to ensure objectivity as my subjective bias may have affected the way I understood and interpreted the data collected. I understood the need to be receptive to the thoughts and views of others and to withhold my experiences so as to identify and understand those of the participants. Furthermore, I made an effort to recognize and convey my specific traits, which could have affected the participants' responses. Below, I disclose necessary information about myself that could have influenced or affected the relationship between myself and participants during the collection of data and data interpretation.

About me. I am a 24 year old, coloured female, who has recently completed a Bachelor of Arts degree in humanities and an honours degree in psychology. During the interviews I was cognisant of the fact that most of my participants were older than me and this may have influenced that extent to which they were willing to reveal sensitive and emotional experiences. Further, some of my participants were older males, and gender dynamics may also have influenced their willingness to share their experiences with me. According to Miller and Glassner (2004), the interview process is seen as an inevitably

gendered interaction. The problem of how participants respond to the interviewer based on who they are in the participants lives, along with the social classes to which they belong, such as gender, age, class, and race, is a matter of concern. This problem may be worsened when a researcher explores groups with whom they do not share membership. Mainly, due to social distances, participants may not trust the interviewer, they may not understand their questions, or they may intentionally misinform the interviewer in their responses. Similarly, if a researcher does not share a membership with the participant, they may not know sufficient information about the phenomenon being studied to ask the correct questions (Miller & Glassner, 2004).

Despite my young age, I embarked on this research with appropriate experience in qualitative research. During my honours I used qualitative research methods in one of my assignments. Furthermore, I attended a week-long training workshop on qualitative research and interviewing techniques. In the workshop valuable research practices, such as a creating a safe place for participants to speak freely and being aware of my own body language, vastly improved the quality and experience of the interviews I conducted.

In terms of OCD, I do not have OCD myself, and therefore do not share an insider perspective of the disorder. However, having some knowledge of the condition helped me to include broad and more specific questions relating to daily functioning and QOL. Interviews were short and once off, and this may have created a distance between the participant and myself so that the person would not want to reveal information to a stranger. Being aware of this, I made participants comfortable with a short introductory icebreaker. Furthermore, there was a participant that mentioned me being a stranger made it easier for her to talk. Being a female and younger than all participants could have also influenced their openness to reveal information. However, participants were asked about how they experienced the interview, several mentioned that I was easy to talk to and that they enjoyed talking to someone whom

was interested and understood their condition. Through self-reflexivity and continuous supervision, I remained aware of the possibility for researcher bias.

3.7. Ethical considerations

As noted earlier, the data were collected as part of a larger on-going study (HREC ref no: M07/05/019). The proposed qualitative study was added as an amendment to the above protocol for ethics approval (approval date: 26 April 2016).

Participants were asked to provide written informed consent prior to taking part in the interviews. Participants were informed verbally and in writing of all procedures related to the interviews prior to consent. They were also informed that their participation is entirely voluntary and that they were free to withdraw at any time of the study and refuse to answer any questions without consequence. Participants were assured that the information (interview notes, questionnaire data, audio recordings) collected during the interviews would only be made available to myself and my supervisors.

Participants were told that additional consent would be obtained from them should the data be used in secondary analysis in future. The data were anonymized and will remain as such in any publications emanating from this work. Furthermore, the data were stored electronically on a password-protected computer. Participants were provided with a R150 travel voucher as a token of appreciation for their participation and time in the study.

This study was considered a medium risk, as some participants experienced anxiety during the interview; however no referral for treatment was requested. There was, however, an existing referral system within the SU/UCT MRC Unit on Anxiety and Stress Disorders at the Department of Psychiatry, SU such as private clinicians or support groups. These details were provided in the consent form (see Appendix E and F).

3.8. Conclusion

In this chapter, I presented the methodology used. I collected qualitative data and analysed it with the aim of answering the following research question: “How does OCD impact an individual’s daily functioning and QOL?” Data analysis techniques and procedures, trustworthiness and reflexivity and ethical considerations were also noted. In the chapter to follow, I report on the results of the data analysis.

CHAPTER 4

RESULTS

4.1. Participants

As depicted by Table 1, 20 individuals (five males and 15 females) took part in the study. Participants' ages ranged from 23 to 69 years. Sixty per cent (N =12) of the participants were married, while (30% (N = 6) were single and (10% (N = 2) were divorced. The majority of the participants (N= 8, 40%), lived with other adults and children, while (35% (N = 7) lived with other adults and no children, and (25% (N = 5) lived alone. Fifty per cent (N = 10) of the participants graduated from a tertiary institution, and are employed full time. The majority of participants (70% (N= 14) received a family income of R15 001 per month and above.

Participants reported different ages of onset of their symptoms of OCD. However, the majority (60% (N= 12) first experienced symptoms of OCD at the age of 12 years. Participants were diagnosed with OCD at different ages; a third (30% (N= 6) were diagnosed between the ages of 35-44 years. Illness severity scores as assessed with the Y-BOCS ranged from 8-34 (M = 22.4 and SD = 6.62). This shows that the average severity of OCD was moderate. Similarly, the severity scores as assessed by the self-report FOCI ranged from 5-18 (M = 10.85 and SD = 4.11), reflecting that most participants had experienced moderate symptom severity over the past seven days (at the time of the interview).

Table 1: Demographics table

Characteristics	n= 20	%
Age (Mean (Standard Deviation) in years)	45.65 (13.82)	
Gender		
Male	5	25
Female	15	75

Marital status

Single	6	30
Married	12	60
Divorced	2	10

Living situation

Live alone	5	25
Live with other adult(s), no children	7	35
Live with other adults and children	8	40

Highest Education level

Completed matric	7	35
Attended university, college or a technikon but did not graduate	3	15
Graduated from university, college or technikon	10	50

Current work situation

Employed full time	10	50
Employed part time	2	10
Student	2	10
Unemployed	1	5
Homemaker	2	10
Retired	3	15

Family income

R2501-R5000	2	10
R5001-R10 000	2	10
R10 001-R15 000	1	5
R15 001 and above	14	70
Unknown	1	5

Onset of OCD symptoms

Under 12 years old	12	60
12-17 years old	3	15
18-24 years old	2	10
25-34 years old	1	5
35-44 years old	1	5
45-54 years old	1	5

Onset of OCD disorder

Under 12 years old	3	15
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18-24 years old	4	20
25-34 years old	4	20
35-44 years old	6	30
45-54 years old	3	15
FOCI scores	10.85 (4.11)	
Y-BOCS scores	22.4 (6.62)	

4.2. Themes and sub-themes

Six themes and 14 sub-themes were identified (Table 2), and interpreted through the lens of Ecological Systems Theory (EST). As such, the theory was used as a guide for organizing and interpreting the results at a latent level. In the following section, each identified theme and associated sub-theme is described and supporting quotations are provided.

The emergent themes are divided across the various ecological systems, which include the microsystem: (i.e. awareness of OCD, and factors influencing daily functioning); the meso-system: (i.e. influence on family and other relationships); the exo-system: (i.e. impact on work and school); the macrosystem: (i.e. services) and the chronosystem: (i.e. changing experience of living with OCD).

Table 2: Themes and sub-themes

Systems	Themes	Sub-themes
Microsystem	Awareness of OCD	
	Factors influencing daily functioning	Impaired cognitive functioning
		Poor quality of sleep
		Impact on daily routine
		Leisure activities and hobbies
		Socializing

Mesosystem	Influence on family and other relationships	Secretive nature of disorder Supportive behaviour Unsupportive behaviour Families' experience of OCD
Exosystem	Impact on work and school	Decline in school and work attendance Impact on productivity
Macrosystem	Services	
Chronosystem	Changing experience of living with OCD	Terrifying experiences Coping strategies Experience of self with OCD

Microsystem. As explained in Chapter 2, the Ecological Systems Theory places the individual within the microsystem. Together with this are the factors directly related to the individual, such as unwanted thoughts and compulsions that influence their daily functioning and quality of life. The microsystem is the innermost environment in which the individual lives, and includes the structures with which the individual has direct contact.

In this study, two underlying themes were characteristic of the microsystem, namely, (1) awareness of OCD, and (2) factors influencing daily functioning.

Awareness of OCD. Awareness of OCD emerged as a significant theme within this system, as participants at a previous point in their life did not recognize that their symptoms of OCD were representative of an underlying disorder. Several participants described their earliest memory of OCD as a normal experience. Some participants explained that they grew up like others around them and were very active. For example, Sally stated:

I thought that it was normal to be this way because I have been this way since I was little. Because everything had to match, I have pictures of myself as a little girl which I looked through again the other day; everything matches, clothes, socks, and shoes everything, even the ribbons in my hair. (Sally, a 62-year-old female, P 11)

Participants failed to recognize that their symptoms were irrational and maladaptive, and it was not until others commented and/or complained that the patients sought help for their condition. For example, Rezaan, who recognized her symptoms of OCD before she turned 12, reported: “I think my mom recognized oh goodness; there is something wrong with this child.... Ja, she took me to various doctors... and I got diagnosed quite quickly” (Rezaan, a 23 year old female, P 13).

While most participants recognized their disorder at a younger age, others recognized it later in life as their OCD affected maintaining relationships, which led them to seek help. Sasha (who was diagnosed with OCD between the ages of 35-44) illustrates this:

So a year and a half back I realized that things that I do that involves my marriage, also involves OCD. I didn't realize it earlier. Something really big happened this year and I got a little out of control so then I read up about it and found out that it was also OCD. I then came to see [clinicians name] and this whole bundle and she then basically diagnosed me and from then on I started receiving treatment. (Sasha, a 37-year-old female, P 18)

Some participants reported having obsessions (n=1), others having compulsions (n=5), and yet others having both obsessions and compulsions (n=14). Many participants felt that failure to comply with the compulsive acts would result in catastrophic consequences: “Um [I] have to do a silly dance while I'm waiting for my food to heat up in the microwave otherwise my mom would die” (Nina, a 29-year-old female, P 17).

These participants described their earliest memory of having OCD. Participants emphasized that the symptoms they experienced helped them and their families to seek the necessary help. Given participants' awareness of their OCD and their symptoms, they were able to elaborate on the influence of OCD on their daily functioning.

Factors influencing daily functioning.

Impaired cognitive functioning. Participants reported that their OCD often left them unable to think clearly. At times their memory was impaired and they could not remember whether they had completed rituals. Consequently, this meant having to perform rituals repeatedly.

And those are things that I'm constantly checking and somehow I could doubt it... I don't have a good memory, but the memory that I don't have is linked to the OCD again because you got all these exchange of thoughts instead of focusing on what you're doing, so it's very difficult to explain to somebody exactly what's happening. (Dirk, a 57-year-old male, P 20)

OCD also influenced participants' decisions to further their education and pursue certain careers, as a result keeping them from reaching their full potential. Some participants were ineffective as students, unable to complete any degree undertaken, while others were compelled to resign from their employment because of the stress caused by their OCD.

Supporting this is the statement by Derrick:

What I know I made major decisions in my life that stuffed up tremendous potential within my life, okay, I don't have any varsity degree or things like that, at that time I didn't know it would be as important as it is today. I couldn't do that all because of my OCD. I did two years' MBChB and I did two year's BA LLB, and but I got no degrees to show for it. (Derrick, a 58-year-old male)

Although participants believed that certain cognitive processes had been influenced by OCD, they also complained that their sleeping patterns had been disturbed.

Poor quality of sleep. Several participants stated that OCD negatively affected their sleeping patterns. Poor quality of sleep was related to difficulties in relaxing prior to going to sleep, and difficulties in preparing for sleep because of persistent thoughts and rituals that had to be performed. Marcy constantly had to get out of bed to check certain items and appliances in the house:

I would lie in bed and think oh I wonder did I check all the taps, and if they are not dripping. Up again, through the house. And I think that once you are in the spinning of that, once you checked the taps, you check the plugs, once you've checked the plugs, you wonder about the taps again [...] (Marcy, a 59-year-old female, P 7)

Participants defined their sleep quality as poor. Not only were they unable to fall asleep, but arbitrary thoughts would disrupt their repose. For example, Rezaan confided that she would wake up with thoughts about becoming ill. She also emphasized experiencing feelings of anxiousness, which further worsened her condition:

Sometimes it happens at night, which is not nice. You wake up at night and feeling I actually don't feel well and then you get this panic disorder and you feeling more anxious. And the more anxious you feel, the more sick you feel, but you are not actually sick... and you cannot call anybody at 1am at night. (P13)

Participants mentioned that OCD affected their cognitive processes and sleeping patterns. As a result of this, their daily tasks also became a problem.

Impact on daily routine. Participants described their OCD influencing ordinary chores such as meal preparation and undertaking shopping trips. These chores were influenced as a result of certain rituals or intrusive thoughts while preparing food (such as the need to cut vegetables in certain ways). Difficulty in undertaking shopping trips resulted from not

wanting to touch certain groceries in the store or not wanting to touch the door handles in public toilets or the railings on the escalator. Here participants were concerned with affecting others or worried about being exposed to harmful contaminants.

I have a lot with food stuff like, uhm, like if I see a lot of people touching an apple for example at a store, I cannot go to that store again, like even if the apples are sitting like on a display and you're supposed to touch them to put it in, my head goes how many people have touched it, how many people haven't washed their hands, I cannot buy from that store anymore, so it's very stressful and debilitating. (P 17)

Some participants also described not being able to concentrate while driving or while others were driving. While, for Jan, completing household chores and managing his children was prolonged by several counting rituals.

When I take out the children's clothes at night for the next day for school, then I will unpack the clothes on the bed and then I will say as I put the shoes down there, then I count the shoes. I kind of love counting and numbers and then I will put out the shoes and then that's one and then I'll count in my head, okay, two is that she took a bath tonight, she put on a clean panty, so two is her panty, three is this and so on. I start at 9 at night with this and at the end I will only get in bed at 12 or 12:30. (Jan, a 39-year-old male, P 10)

Leisure activities and hobbies. Several participants stated that OCD did not allow them time to relax or engage in recreational activities, as many of these activities triggered symptoms of OCD. Activities such as reading, watching TV, going on holiday, exercising, participating in sport and hobbies, were severely disrupted. Maria remarked that OCD influenced her activities such as relaxing and watching TV:

When I'm watching television or a movie, the last sentence that somebody has said, I will type the words in my head, I will like if you say OCD, I will go CAPS, OCD,

uncap, and then sometimes I lose my train of, you know I miss a sentence, or I miss something because I've been busy typing, so that I actually do even when I'm relaxing. (Maria, 38 year-old-female, P 5)

For Dirk his OCD prevented him from travelling and sightseeing while on holiday. He stated:

I was travelling overseas and then I used to, you know, go back and I used to check things to such an extent that I think I miss out on what I was actually meant to be doing and seeing and stuff. (P 20)

Sasha described how her OCD takes over when exercising. However, she is unsure as to whether this is caused by her anxiety or by the OCD.

Yes especially when I'm alone, I would be counting most of the time yes, either the thoughts in my head or my steps, I match my breathing to my steps when I run especially.... I have social anxiety so it makes relaxing activities more difficult for me... But yes, it's difficult to say if it's OCD or just anxiety. (P 18)

Spending time with pets or relaxing at home often triggered symptoms of OCD. Heather suggested that being at home triggers her symptoms. She finds it relaxing to visit others, her OCD not being triggered then:

Most of the time it is when I'm at my own house, because at other people's houses it doesn't bother me, I like my stuff to be neat. If I must come to visit you it wouldn't bother me if there is dust lying around or if it's untidy, I enjoy visiting there, it's comfortable for me. Its only at my own house – I don't know what it is here that triggers me. (Heather, a 64-year-old female, P 8)

Furthermore, participant's also explained the influence of OCD on their social development.

Socializing. Several participants were unable to establish new and maintain social relationships as OCD concerns prevented them from going out or attending social gatherings. For example, Wendy, who was single, intimated that her OCD, particularly the fear of sexual relationships associated with her OCD, influenced her previous relationships: “I have never had a boyfriend, never so... maybe I was different, maybe my body language and everything was different, because of the OCD” (P 14). Stuart described his OCD, together with his depression, prevented him from attending social gatherings and becoming isolated, “because with me OCD came with depression as well. So I was OCD, depressed, didn’t wanna go out, what did I enjoy? What I enjoyed was sleep, I just slept” (Stuart, a 47-year-old male, P 16). Furthermore, Jan revealed socially withdrawing himself from his peers as they failed to accept his condition when rituals consumed his time: “So my social circle (and it’s my own choice in my head) has shrunk a lot, I miss probably 80% of all social events, something I didn’t do when I was younger” (P 10).

Other participants offered descriptions of the influence of OCD on them while socializing. For example, Kelsey told of her intrusive thoughts while she conversed with people:

For example yesterday we went out for a bit of lunch, I can’t, if my mind suddenly has these horrible thoughts about things happening to people I love, I can’t look at them. So my mind’s thinking all these things, meanwhile I’m trying to have a conversation, so it does interfere with things. (Kelsey, a 31-year-old female, P 4)

It was evident that OCD consumed the lives of individuals as it influenced their ability to accomplish tasks of daily living.

Mesosystem. In this study, the underlying theme representative of the mesosystem was the relationships between the individual and his/her family members, friends, and colleagues.

Influence on family and other relationships.

Secretive nature of disorder. Participants stated that they preferred to keep their condition private from family members and friends. Participants provided several reasons for maintaining the secrecy of their disorder from their family, including that there was simply no need to tell their family members (this pertained more specifically to not telling their children). Others stated that their families would not be interested or would not support them, while others reported that their families were not trustworthy and would judge them. Sasha stated that she did not trust her mother to respect her privacy. Sasha believed that, had her mother revealed her condition to others, they would have judged her:

And I don't really speak to anyone about it... because I find that you kind of get defined by it, if people think of you they think of (participant name) with OCD and I don't want that. I don't really trust my mom not to speak to her sisters about it. (P 18)

Other reasons were offered by participants in support of their remaining silent about their disorder. Reasons included participants feeling that their condition was personal and feeling too embarrassed to disclose. While some participants kept their condition a secret owing to shame, others stated that their friends or outsiders would judge them, given their lack of understanding of the condition. For example, Rezaan maintained that her condition should be kept private in the interests of saving face:

No, I don't share it with a lot of people actually. I do share it, but I feel that it is a personal thing and it is difficult to explain to people... I think yes, I am partly embarrassed and on the other side I don't think they will know what to do. So maybe embarrassed and they wouldn't know what to do and I just think it's something personal, not something you should be proud of. Not something you should "boast about." (P 13)

While participants reported being selective about whom they disclosed their OCD to, this did not necessarily restrict all sources of support.

Supportive behaviour. Participants who chose to disclose to others were able to gain valuable sources of support, such as physical, emotional, and financial support, “When I was diagnosed with OCD they were very supportive, very, very supportive. In terms of financially supporting my therapy, financially supporting my education, and emotionally supporting me etc.” (Stuart, P 16).

Participants reported that, as a means to provide further support, family members often became involved by seeking help, taking part in rituals, and providing constant reassurance.

I would ask my children..., they all drive- they all big and I would ask them to ride to a specific corner and go and check if there is not a cyclist going there. In the end I think they might have done it once or twice. (Rheinart, a 55-year-old male, P 15)

Participants’ family members not only took part in their rituals, but also tried making things easier for sufferers whose OCD seemed overwhelming. Participants stated that family members would try to minimize situations that could trigger their OCD. For example, Judy explained the way in which her husband would block the triggers to her OCD:

Often in the past I for instance closed taps, eventually my husband took off the plugs because I just couldn’t get away, switching off lights, hiding the iron because I was scared it will hit the wall, things like that, there were compulsions. (Judy, a 33-year-old female, P 19)

Several participants said that family members used humour as a means of ameliorating certain situations. Other participants stated that their families understood them and their condition and therefore tried motivating and calming them down during problematic

circumstances. For example, Rezaan, who lives with other adults and children, told of her mother motivating her when she displayed OCD symptoms:

My sister is two years younger than me. So she can remember most of the things, she would usually tell me so when we drove to school, especially in primary school – just to get me relaxed, because I was working myself up until we get to the school gate. My mom had this exercise for me where I must count the telephone poles, so I can just get distracted. I mean I needed to be motivated all the time; I needed to be relaxed all the time. (P 13)

Participants reported that, without the support of their family, they would have found living with their condition exhausting. Some participants explained that, overall, they had gone through difficult times with their families. However, the necessary support had prevailed and strengthened their relationships.

Participants also described the support they had received from friends. Here again, humour and understanding were helpful in overcoming the challenges of the condition. For example, Marcy affirmed that her friend humours her condition and this makes it easy and comfortable for her to discuss her condition openly:

Yes no, no, no we support each other all the time. I've got a habit of deleting things on my computer you know, it's also OCD just not wanting clutter, and I mean, then we phone each other, you won't believe what I've just done. Then we phone and we laugh at each other because we understand the compulsion to delete the thing, you know, so no we share our stories with each other we laugh all the time because it there is a funny side of it, otherwise we'd all be depressed. (P 7)

Several participants outlined in detail the ways in which their colleagues supported them, which makes it easier for them to work. Support included accommodating them (through understanding and acceptance), offering compliments, and participating in their

rituals. For example, Rheinart, who is employed full time, reported that he involved his colleagues in his rituals (through reassurance) as they knew and understood his condition:

She went to go and check the parking area once or twice or check the ashtray once or twice. Yes but her and I work together for donkey's years so some of my colleagues they know about it [...] (P 15)

Another participant, Dirk, also employed full time, stated that his colleagues had come to understand him and this made it easier for him to talk about his OCD at work: “Even at work I talk about it because I feel people can understand you better if they know but not everybody, I don’t tell everybody but my immediate people around me at work so that they know me” (P 20).

Based on participants’ reports, they had had significant support from their family, friends, and colleagues throughout their experience of OCD. This support has helped them to continue with their lives – socially and at work – despite the OCD. Participants also explained several instances of unsupportive behaviour.

Unsupportive behaviour. Participants described that unsupportive behaviours were recognized as an inability of certain family, friends, and colleagues to accept and show empathy towards them and their condition, for example:

I lost all my friends and then they used to spit on me and hit and ja, it was push me so it was ja, and rejected completely like it was – I think that is why I am the way I am, because I carry a lot of fear of rejection. Because throughout like my illness, a lot of my friends left me and stuff, all my friends actually and then obviously the bullying and all of that as well. (Wendy, a 26-year-old female, P 14)

Further, unsupportive behaviours were seen as an inability to understand the nature of their illness and inadvertently triggering OCD symptoms. For example Stuart, who is married

and lives with other adults and children, explained how his wife reaction to his condition was perceived as negative:

She didn't like this; she basically kicked me out of the house because she couldn't cope with the OCD... So her reaction was very negative and very ruthless and very cold. Uhm, she couldn't quite understand why I was doing this. For instance when I was driving... With my wife, she got irritated and shouted and performed and said "stop the car I'm gonna drive, you can't drive anymore." (P 16)

Even though several participants hid their condition from certain family members and friends, whether or not they received support, their condition still affected the way in which others, particularly family members, processed their diagnosis.

Families' experience of OCD. Several participants perceived their condition to be traumatic to their families. Wendy, who lives with other adults and no children, explained that her OCD affected her relationship with her parents: her parents displayed emotion that reflected their devastation: "my mom would just sometimes cry in the other room and my dad would just be outside... I think it has caused a lot of irreparable damage to my parents and my brother" (P 14).

Participants also described the influence of OCD on their relationships within other important domains of their lives.

Exosystem. In this study, there was one underlying theme representative of the exosystem, namely, impact on work and school.

Impact on work and school.

Decline in school and work attendance. Several participants related that OCD inhibited them from attending classes or lectures. Participants stated they were often preoccupied with checking or performing certain rituals or dealing with intrusive thoughts,

such as worrying about their health. For example, Rezaan, who completed matric, reported a drop in her school attendance through fear of illness:

I missed a lot of school and things, because I would literally get this fear of I will get sick at school or I would feel like I make myself sick, not intentionally. But I feel like oh goodness, my stomach just grumbled maybe I am getting sick, and then you make yourself sick. (P 13)

For some participants, OCD affected getting to work on time. These participants experienced being late for work or meetings and/or less work attendance very often, and considered this a result of their OCD symptoms. Rituals, such as checking whether appliances were switched off at home, or driving around to make sure that they did not have an accident or knocked someone over, took a substantial amount of time.

So going to work, I get to the door, I lock the door and I think something, and once I get in that house, then everything has got to be checked again, the taps, the switches. So yes, it could have taken me an hour back and forth. Every time I lock the door, I think but was the iron out. Once I get back in there I am like a wild thing, because now I can check everything again. Then I lock the door and wonder if the kettle is off, so back in the house I go, right through this whole thing again. (P 7)

Participants offered their debilitating experiences prohibiting them from attending school, varsity, classes, lectures, or work every day. Because of this, participants' productivity at school and work were also negatively affected.

Impact on productivity. Several participants mentioned that OCD affected their academic and work performance. Participants could not complete tasks because certain rituals (such as double checking and proofreading) had to be performed during note-taking, reading, studying, or completing other tasks. Participants reported that they took longer study for examinations and to complete work as they were unable to focus and concentrate, being

plagued by constant rituals and thoughts. Angela, who graduated from a tertiary institution, said that she could not complete her examinations, because of the compulsion to recheck answers:

Accounting exams, I never finished to accounting exams because I had to check my work three times. I'd checked all the sums, then I'd get to the end and [clicks] there's a doubt. What happens if this answer, what happens if I made a mistake on the calculator, start again then I get a different answer and now, well I've checked twice but it means nothing because I got two, I've gotta check again, and I never finished accounting exams. (Angela, a 40-year-old female, P 6)

While some participants experienced a decline in school and work attendance and an effect on their productivity, others adjusted and performed well since they were stricter with themselves and went to great lengths to instil routine and manage their work load. Several participants completed university degrees while living with OCD. During this period, they set high standards for themselves and therefore managed to achieve more. However, this was also seen as stressful. Stuart, who graduated from a tertiary institution, became so obsessed with his studies that he compelled himself to study even harder:

I think it was detrimental to my academic performance because I studied too hard, I was obsessing with my studies and it was also kind of at the same time an escape. So I would study for 14/15 hours a day, especially in my honours level, I would work work work until 12 o'clock at night, go to sleep, wake up at 6 and work work work read read read whatever until 12 o'clock. I think I over-obsessed studying. Studying became, especially an honours year, became an obsession in itself. I had to study or I was gonna fail I couldn't go out to see movies because that would be wasting time... I didn't go out to relax on the weekends because that would be wasting time. If I

wanted to pass I needed to work 100% and 100% meant maximum amount of hours every day. (P 16)

On the other hand several participants found some positivity in their work from their OCD. This positivity included advantages of such factors as saving time when searching for items – OCD made some sufferers organize items in a certain way and in certain places. Most participants who celebrated the positive side of their OCD were those employed in the art world. Art allowed them to be free and creative. Some participants would apply their OCD perfectionism to their work, for instance, ensuring that relevant items were neatly pasted, while others would use their counting as a way of being creative in their art, such as using every fifth word or letter to create film scripts. These sufferers believed that their OCD made them and their work unique, subsequently making them successful at work. Lucia, who is employed full-time, stated that her OCD has created success in her ability to produce significant work:

I think my OCD is an advantage in my art, I think it is an advantage because it makes my work unique and it gives my work a very definite... So it is very positive in the art world... I don't think I would have been able to do art if it wasn't for my obsessions.
(Lucia, a 55-year-old female, P 12)

Although some participants experienced difficulty or hindrance in their academic life and work, others were open to adjusting to their OCD, allowing it to take some control of their academic and work performance. It was evident that the participants' academic performance and work activities were severely affected by their OCD. As a result of this, and the previously mentioned influences (such as the effect on daily functioning and relationships), participants made use of the broader environment to assist with treatment and relief from their experience of OCD.

Macrosystem. In the context of this study, the macrosystem consisted of the individual's treatment that was sought, and the effects of these on their experience of OCD.

Services. Several participants stated how helpful their psychologists, psychiatrists, and doctors had been during their experience of OCD through reassurance, understanding, and offering therapy services (CBT). Supporting this, Sandra added that her psychologist had been very helpful in assisting her to remain healthy and well-balanced:

I see a psychologist regularly where I just talk about everything and it makes me feel that I am normal and not busy going crazy. It is part of the disease and you try to live with it every day, but you have to go for that support regularly. You can lose track so easily if you don't have that support. So yes I think that it helps you to stay on track and keep you sane. (Sandra, a 39-year-old female, P 9)

Other participants received their assistance through online support groups. For example, Judy has access to online support groups for OCD. Participating with other sufferers allows her to restore her health:

I am on so many media groups where I read up about other people's experiences and then I realized as I was reading their experiences that I can be thankful I'm not in a job the entire day or that I can be thankful that I'm still able to work because I know there are people that is so effected that they physically cannot work anymore. So I think what worked for me to make it more bearable was to go sit and read books, read on the internet and to follow social media, OCD drive it's like Facebook for OCD people to go on it and become a part of other peoples stories. In the process, you bring yourself healing and you also realize that what you have to deal with is less than other people have to deal with. (P 19)

Several participants mentioned that the healthcare services which assisted them in maintaining healthy living with OCD had been readily accessible. As participants described

their experience of OCD and its influence on their daily functioning and quality of life, they related further details regarding the fluctuations of living with OCD.

Chronosystem. In the context of this study the chronosystem considered the changes over time in participants' experiences of OCD.

Changing experience of living with OCD. Participants' experiences of their OCD changed over the course of their lifetime. Here, three sub-themes emerged, namely terrifying experiences, coping strategies, and experience of self with OCD.

Terrifying experiences. Participants described that over time their intrusive thoughts and rituals became disturbing, destructive, and debilitating in their environments.

Specifically, participants described feeling as though they had little control over their symptoms and therefore required more support from their close networks. Furthermore, participants also explained their experiences of living with OCD as terrifying, because they shifted this worry about themselves to worrying about how others would perceive them, all the time keeping their disorder private. For example, Sarah articulated her constant anxiety about her thoughts, not being able to control it, which caused her feelings of fearfulness: "It did for me, I couldn't tell anyone because it felt for me like I really caused his death, and it bothered me a lot, it bothered me a lot" (P 1).

As several participants described their experience of OCD as disturbing and frightening, as affecting their lives so drastically, over time they started developing feelings of irritation, anger, sadness, discomfort, disgust, and embarrassment of having to live with their condition. Supporting this is the statement made angrily by Kelsey that she had had enough of having to live with OCD, venting her distress:

I'm pissed off about it. I'm gatvol I've had enough of it, like I've been dealing with it since junior school and I hate my thoughts, I hate my little ticks, so some days maybe a teensy bit satisfied but overall I'm not satisfied, no. (P 4)

Participants also mentioned that OCD constantly brought about feelings of fear and anxiety and was therefore stressful. It is important to note that some participants experienced other aggravating symptoms along with their OCD. For example, Rezaan confided that she is constantly anxious, always worrying about everything, therefore always feeling stressed: “It is not a nice experience to have because you have this constant fear, you stress literally all the time and you stress over things that are never going to happen and this pessimistic view of life” [...] (P 13).

From participants reporting on living with OCD as unremittingly alarming, their worry eventually shifted towards wondering how they could adjust to their condition. In this way, their terrifying experience reduced over time.

Coping strategies. Over the years participants have found various ways of adjusting and coping with their condition, reporting an improvement in their condition over time. This sub-theme is further categorized, namely 1) problem-focused coping, and 2) emotion-focused coping.

Problem-focused coping. This category examined ways in which participants tried, through avoidance, to solve the problem of OCD itself. Several participants mentioned that they avoided actions that would trigger their obsessions, such as reading certain sections of magazines or driving. For example, Maria confided that she avoided reading certain sections of magazines to lessen her disturbing thoughts of being gay:

I would avoid the magazine section because I would be afraid of what I may see...when I look at a picture of a woman that's naked or you know breasts shown you see it on a, you know there's the magazines that you see that then I think you know, she's gonna great body she's hot, or what then I would think well this, this is not normal, maybe I'm gay. (P 5)

Several participants stated that they actively avoided situations that were likely to trigger their compulsions. For example, preparing toys for children to avoid them making the house untidy; or avoiding to buy items that needed to be cleaned: “Often when I want to buy something, I first look, then I look at it, then I think to myself that thing needs a lot of cleaning – I don’t think I am up for it” (P 8).

Ironically, two participants who have the compulsion for cleanliness and orderliness have sometimes avoided cleaning or having to live in perfect orderliness by allowing chaos to takeover in their room or house because in this way, they felt unbothered. Derrick, in his drunken state, prefers things to be messy so that he can avoid orderliness:

I used to actually mess up everything in my room in my drunken state I could handle the chaotic state okay, and with the thing that one day I’ll fix it up and I’ll get it back to that perfect state, but right now I’m happy like this. If it was too anyway close to that perfect state, I was scared that I wouldn’t be able to resist doing that and ya okay, so that became sort of easier. (P 3)

Emotion-focused coping. Participants shifted from attempting to first solve OCD itself to attempting to solve the emotions associated with their OCD, as they felt they needed to change the way they felt about their condition. Participants found several ways of coping with their OCD, including adjusting to certain triggers. This included mechanisms such as talking to themselves, convincing themselves to stop what they were doing; reassuring themselves that everything would ultimately be resolved, or praying and asking for help. Chloe prays for strength and guidance to help her cope with her intrusive thoughts: “I have learnt to say something; I always say ‘cancel all negative thoughts in the name of God’. And it sort of helps. It lets me, lets me get a higher power to take those thoughts away” (Chloe, a 69-year-old female, P 2).

Other participants prepare themselves for situations that may trigger their OCD.

Rezaan explained how she carries her pills with her to prevent an OCD reaction, in her case, from her thoughts about falling ill: “I prevent, for now I carry pills with me for that feeling” (P 13).

Another coping strategy used by participants was writing down notes on events, situations, or triggers, which might set out quite clearly in their minds the irrationality of their OCD. “So I learned a lot of methods to write it down and it also works to read it to yourself over and over and over and over and over again until you realize how irrational it is” (P 19).

Participants also coped through strategies such as using humour. Several participants prefer to be distracted by keeping busy, such as working, taking part in exercising or sports, or talking to friends and family. Derrick masks his OCD by constantly working. This relentless activity does not allow him time for other activities, such as leisure and social activities: “I have very little life at the moment other than work because I’m so tired all the time and when I’m not working then I just need to sleep you know” (P 3).

While some participants described that being at home triggered their OCD, others adjusted to this and found themselves assisted at home in coping with their condition. These participants felt perfectly at ease while at home. On the other hand, several participants also used coping strategies such as comfort eating or drinking alcohol to cope with their OCD. Kelsey drank alcohol to mask the emotions associated with her OCD: “It was horrible. Horrible. I went through a very bad patch, ya I went through a stage where I drank a helluva lot just to cover up what I was feeling” (P 4). Then again, Heather overeats so as not to think about cleaning:

I go sit in front of the TV and eat nonstop. It’s almost like “binge eating”... Then I decide that I have to eat something immediately, I think I have to go buy myself something to eat because I have to sort out the things later again. (P 8)

While several participants made use of their own coping strategies, some believed that their medication has helped them manage their OCD. For example, Chloe who takes Paroxetine Hydrochloride also used her own coping strategy of praying. Chloe believes that her medication has improved her quality of life:

when I was on [name of medication] for three months, I told him ‘you know, I didn’t know there is life after life’. It was wonderful; it was a wonderful experience to know that so many years of my life was not a quality life. (P 2)

Other participants reported that solely using their medication had assisted them in coping with their OCD. For example, Stuart who uses Aripiprazole maintained that his medication was the only way of helping him cope with his OCD, thereby living a better life:

If it wasn’t for the medication I think I would still be in OCD status... I believe that is what changed from black to white for me, counselling and therapy, no, no. I don’t think, again, I saw six or different psychologists or counsellors and none of them helped with the symptomology. The medication, is for me personally, the route to what made it asymptomatic. (P 16)

Although several participants described their experience of living with OCD as frightening, they reported ways of controlling their condition. For these participants, control provided a level of acceptance of their condition over time and allowed for them to lead a normal life. Marcy stated:

So I am happy to check in the evening or when I go out now... I am quite happy with checking in the evening and driving a little bit back now and going to check the garage door or...no. It is not that I would now say I will now want to take medication because this is like too much. It’s sometimes it’s “lasting” you know but I could live with that. (P 7)

Another participant, Lucia, also grew to accept her condition over the years, “I think with time I have learnt to accept it and I know it is actually something that makes me unique in a way” (P 12).

Participants’ experience of their OCD, the effect that it had on their daily functioning and quality of life, their control and management of it, boosted their self-esteem.

Experience of self with OCD. Participants also found their abilities positively affected once they started better managing and understanding their OCD. This sub-theme is further categorized into two categories, namely self-esteem and self-efficacy.

Self-esteem. Several participants stated that their OCD had fostered a lack of self-esteem. They saw themselves as weak, bad, imperfect, and they saw their lives as almost unbearable. Sarah’s experience has changed her as a person from being strong to being weaker: “I felt so bad...it's just that I see myself as weaker...Yes it bothers me because I was always a strong person but I no longer am” (P 1).

Other participants constantly felt self-conscious, being concerned with others’ attitudes towards them. Wendy, for instance, fears what others may think of her, because she is afflicted:

I am a very like self-conscious person so I am very nervous so I always care what people think of me. I think it also stems to when I was at school, probably one of my worst memories was when I was at general primary and I was bullied, because obviously they didn’t, kids didn’t understand. (P 14)

Many participants admitted to a lack of self- confidence. Jan has low-self-esteem, struggling to accept himself:

As I got older and as life became more difficult I realized that things aren’t really as you thought they were, and so you got a reality shock and your confidence became less. I almost want to say that my entire high school career, university, even the first

few years of farming, I had a very low self-esteem. I sometimes still struggle to convince myself that I am not as bad as I think I am. (P 10)

Several participants also started questioning “Why me?” regarding their disorder. Rezaan, who fears falling ill, has low self-esteem. She has started questioning why she, in particular, has to be burdened by this impediment:

I must say at some point I felt like I had quite a low self-esteem, especially in the beginning of high school with this whole story of – I am scared of getting sick, it is just – you shouldn’t be scared of getting sick, scared of people around you getting sick. So I think personally I had quite a low self-esteem. What was wrong with me, why am I like this, why am I not getting better etc... sometimes I think it is still a bit “Ag, goodness now I need to go through this which other people don’t need to go through.” (P 13)

Some participants experienced extreme desperation leading to thoughts of suicide. Such participants found having to live with OCD almost unbearable.

There were many times where I wanted to take my life, years ago and stuff and I used to cut myself but I think and I have also taken meds but I never really, I knew in my mind and my heart that I didn’t want to die. (P 14)

Nevertheless, other participants stated that their entire personality changed while living with OCD. However, while several participants experienced a negative effect of OCD on their self-esteem, other participants’ OCD, displayed some ambivalence: while negatively affecting them, it made them better people. Nina has become more compassionate towards others: in this sense her condition has enhanced her as a person:

Uhm I think, what’s good is, it has made me more empathetic with people that have with mental disorders because I know what it’s like uhm, also, just even if they don’t, always just thinking you know there’s something that’s going on in their life that you

don't know about so cut people some slack and be kind whenever you can, uhm, personally, I think it has made me a better person but still if you had given me the choice of whether or not I would want it I wouldn't want it. (P 17)

Participants' OCD negatively affected their not only their self-esteem, but also their self-efficacy. However, over time, this experience allowed them to develop into better individuals.

Self-efficacy. Several participants reported that OCD not only influenced the way they see themselves, but also their view of their ability to accomplish things. Participants understood that they were less able to accomplish certain tasks than individuals without OCD. Kelsey, for instance, has no self-confidence, believing that she is inferior to others:

I look at people and I think wow you've accomplished so much, how did you get round it how did you do it, how did you travel alone, how did you study this, you know, and I feel like, I've never had the strength. I don't have the confidence, I'm worried constantly what people will think of me if I slip up, or people see me do what I need to do, I just have no faith, ya. And it's come from a long long time of, ya, since being here, ya. I don't think that I can accomplish much because I don't believe in myself. (P 4)

Despite feeling that OCD had affected their ability to perform tasks, their achievements had given them a boost in self-confidence. Angela confided that when her OCD allows her to be productive at work she feels that she has accomplished something: "I think when you start on a good footing at work and you are productive you feel better about yourself, you've achieved something" (P 6).

Another participant, Stuart, stated that furthering his education has improved his view of his ability to achieve: "Now that I've got a PhD I feel a bit better" (P 16).

It is evident that OCD has played a major influence on the way in which they value themselves and their abilities.

4.3. Summary of findings

In this chapter I presented the results of the qualitative analysis, including the main themes, sub-themes, successfully answering the research question posed in Chapter 1. I conducted 20 interviews with individuals (18 years and older) with OCD. Resulting from a process of thematic analysis, several themes, sub-themes, and further categories emerged, from which I gathered important information regarding the influence of OCD on daily functioning and quality of life. I discussed the main themes and sub-themes that emerged from participants' expressions which they had in common, according to the theoretical framework of the EST, and in detail, using quotations which I believed described the essence of each theme. The information obtained during these interviews provided significant insight into the major role played by OCD in the lives of participants, their daily functioning, and their quality of life, and how this experienced has changed over time. A discussion of these results is presented in Chapter 5 below.

CHAPTER 5

DISCUSSION AND CONCLUSION

This study aimed to explore how individuals with OCD subjectively experience life. To my knowledge, this is the first South African study to qualitatively explore factors that may influence the day-to-day functioning and QOL among OCD patients. The findings suggest that individuals with OCD have to overcome several factors related to themselves, their families and the broader environment in order to maintain a satisfactory QOL. In keeping with Ecological Systems Theory, Chapter 5 discusses the study findings by looking at the levels of the micro-, meso-, exo-, macro-, and chronosystems (Bronfenbrenner, 1979).

Microsystem

Two overarching themes were illustrative of the microsystem, namely, 1) awareness of OCD, and 2) factors influencing daily functioning.

Awareness of OCD. Participants in this study initially failed to recognize their symptoms as atypical and required the motivation and support of family members to encourage help-seeking behaviour. Research suggests that individuals with OCD sometimes lack insight into the excessiveness or irrationality of their symptoms (Besiroglu & Agargun, 2006). They often perceive their behaviour as normal, as individuals without OCD also experience similar symptoms, particularly obsessive thoughts (Abramowitz et al., 2002; Adams, 2016; Insel, 1990; Langlois et al., 2000a; Langlois et al., 2000b). Jorm (2011) proposes that a lack of disorder differentiation (i.e. lack of recognition) may be a significant barrier to seeking help. In other words, having limited knowledge and/or poor insight about the disorder makes recognition challenging. Moreover, insight into one's disorder and recognition that there is more to be concerned about than just superstition or habit may be influenced by stress or discomfort and symptom severity (Gulliver et al., 2010; Jorm, 2011).

Several respondents only sought help when prompted by family members, which for most, occurred at an early age. Individuals with OCD are more likely to seek help when their external behaviours (i.e. compulsions) are recognized by family members (Besiroglu & Agargun, 2006). As family members recognize this behaviour they may either pass judgement on it or encourage patients to seek help. Although most participants' symptoms of OCD were recognized at an early age, others' symptoms were noted only later in life. For example, some participants described the influence of OCD on their intimate relationships, which usually start during or after adolescence. Abbey, Cloptom, and Humphreys (2007) report that OCD negatively correlated with relationship satisfaction and intimacy in their study. In addition, there is evidence to suggest that divorce and separation rates amongst individuals with OCD are higher than those without OCD (Regier et al., 1990; Subramaniam et al., 2012). For example, in a study conducted in Singapore, Subramaniam, Abidin, Vaingankar, and Chong (2012) found a significant association between divorce and/or separation and OCD, with those who were divorced and/or separated holding higher rates (9%) of OCD. However, not all studies agree; some actually reported a low divorce rate (3-5%) for married individuals with OCD (Boyd, 2008), suggesting that not all patients with OCD have difficulty in this domain.

Consistent with the majority of patients in other studies (Foa & Kozak, 1995; Mancebo, 2008; Shakya, 2010; Tanidir et al., 2015), participants in this study experienced both obsessions and compulsions (as opposed to experiencing just obsessions or just compulsions). According to Coles, Heimberg, Frost, and Steketee (2005) patients with OCD often describe their obsessions as irrational and compulsions as a means to reduce their feelings of anxiety or incompleteness caused by these obsessions. Consistent with other studies, most patients fear that the failure to do certain compulsions would lead to severe consequences or catastrophes. In a study conducted in the United States, 60% of participants

identified a catastrophic consequence that they were afraid would happen if they did not complete compulsions, and 40% of participants identified a distressing experience that they thought would be a consequence that they were afraid would happen if they did not complete compulsions (Tolin et al., 2001).

Factors influencing daily functioning.

Impaired cognitive functioning. Participants stated that OCD rendered them dysfunctional and influenced their thought patterns, memory, and decision-making ability, amongst others. Research has indicated that significant impairment in OCD individuals is related to impaired cognitive abilities, reduced mobility, diminished housework and/or childcare (Koran et al., 1996; Besiroglu et al., 2007). More specifically, individuals with OCD often report being uncertain as to whether or not they performed certain behaviours or whether they simply imagined performing them (Van den Hout & Kindt, 2003; Zitterl et al., 2001). These uncertainties may progress to obsessional doubt that increases the need to repeat compulsive acts (Muller & Roberts, 2005; Zitterl et al., 2001). Tallis (1997) suggests that the repetitive nature of the obsessions and compulsions may be as a result of information processing deficits. Furthermore, Hermans, Martens, DeCort, Pieters, and Eelen (2003) argue that repetitive compulsive acts promote self-doubt as individuals do not seem to trust their memory of performing an action. Therefore, it is possible that self-doubt perpetuates deficits in confidence rather than deficits in memory. Together with this feature of uncertainty in OCD, individuals with this condition often report difficulties in making decisions or making choices. Participants in this study reported making mistakes in terms of important life decisions, e.g. in choosing which degree to study for, how much to study, and their choice of career. According to Rocha, Alvarenga, Malloy-Diniz, and Corrê (2011), impaired decision-making seems to be an important aspect of OCD.

Poor quality of sleep. Data on quality of sleep in OCD is not consistent, with some studies (including this study) stating that OCD patients have difficulty sleeping and attribute this to their OCD (Paterson et al., 2012; Storch et al., 2007), and others noting that sleep is intact (Ariaga, et al., 1995; Hohagen et al., 1994). Participants described poor quality of sleep as debilitating and demanding of their time, particularly before going to bed at night as certain rituals have to be performed (Coles & Sharkey, 2011; Insel et al., 1982).

Impact on daily routine. Respondents in this study found it challenging to complete ordinary daily chores, mainly as a result of prolonged periods of performing rituals such as counting and cleaning, as well as of intrusive thoughts. These thoughts and behaviours often become so distressing and time-consuming that it may be difficult or impossible for individuals to get on with and manage daily activities (Mellors, 2006; Palermo, 2014).

Leisure activities and hobbies. Respondents in this study reported that OCD did not allow them time for recreational activities. Consistent with other studies, participants found it challenging to take part in voluntary extramural activities, as many of these activities triggered symptoms of OCD (Storch et al., 2006). In addition, individuals with OCD are often uncomfortable with unplanned or spontaneous leisure activities and are known to spend a considerable amount of time planning these. For example, some individuals with OCD insist on planning their vacation in minute and unnecessary detail, causing severe anxiety and waste of time (Boyd, 2008).

Socializing. Socialization may be a challenge for individuals with OCD as they often report having reduced social skills, self-esteem, and social acceptance (French et al., 2009). These individuals often report feeling rejected by their peers. Withdrawal from social situations is problematic in that individuals are likely to become isolated (Steketee, 1997; Stengler-Wenzke et al., 2007). Findings from this study demonstrate that social withdrawal is a consequence of preoccupation with compulsive rituals or intrusive thoughts. As with their

intimate relationships, OCD patients also report impairment in other social relationships (Fischer, 2009; Hou et al., 2010; Piacentini et al., 2003; Van Noppen et al., 2006). For example, in a study conducted in the United States among 92 children with OCD, participants reported difficulty in forming friendships, maintaining relationships, partaking in suitable social age group activities (such as visiting or sleeping over at a friend's house, and attending social gatherings (such as going on a date or going to events)) (Langley et al., 2004). These findings are similar to those of other studies (e.g. Piacentini et al., 2003).

Mesosystem

The underlying theme representative of the mesosystem is the interaction between the individuals and their family, peers and colleagues.

Influence on family and other relationships.

Secretive nature of disorder. Some of the participants of this study reported concealing their condition from family and friends for several reasons, including stigma, their perceived lack of interest, untrustworthiness, shame and embarrassment. This ties in with other studies that have suggested that help-seeking or treatment-seeking behaviour is often delayed due to fear of stigma, embarrassment, and interpersonal vulnerability (Vogel & Wester, 2003). Individuals with mental illnesses worry excessively about stigmatization and believe that their illness may be perceived as an indication of weakness, or that it could negatively influence their social status (Corrigan, 2004; Schomerus & Angermeyer, 2008). Stigma is a concept that is frequently explored in the context of mental health and several studies have shown a conflicting relationship between stigma and decisions to seek treatment (Corrigan, 2004; Schomerus & Angermeyer, 2008). These barriers often prohibit individuals with mental health illnesses from informing relatives about their condition prior to seeking treatment (Chen, 2002; Goodwin et al., 2002; Jorm, 2000; Kessler et al., 2001; Singh, 2002; Welfare, 1993). In a study conducted in Turkey, the authors found that 30% of individuals

with OCD did not seek healthcare because of their uncertainties and worries about being judged negatively by others (Besiroglu & Agargun, 2006). In a South African study, a participant reported keeping her OCD a secret from both her mother and husband because of their unsympathetic reaction towards her condition (Spragg, 2013).

Supportive versus unsupportive behaviour. Participants reported both supportive and unsupportive behaviour from family members, friends and colleagues following disclosure of their disorder. The process of disclosure was mostly perceived as rewarding, often leading to increased physical, emotional and financial support from significant others. However, as found in this study and others, family support and involvement may exacerbate dysfunctional behaviours (Amir, et al., 2000; Renshaw et al., 2005). For example, in this study participants reported that members of their family often became involved in their compulsive rituals. Several studies found that the participation of families in rituals resulted in poorer family functioning and more severe OCD symptoms for the individual with OCD after behavioural treatment (Amir et al., 2000; Calvocoressi et al., 1995; Steketee & Van Noppen, 2004). Such participation by family members may lead to greater impairment in the patient's QOL, because it maintains their OCD behaviour and as a result impairs their recovery (Stengler-Wenzke et al., 2006; Albert et al., 2007). Behavioural treatments have proven successful once family involvement in rituals was reduced (Steketee & Van Noppen, 2004).

Some participants also experienced unsupportive behaviour from significant others following disclosure of their symptoms and/or diagnosis. Here, participants expressed the inability of others to understand, accept and show compassion. Disclosure of a mental disorder often includes personal costs such as experiencing disapproval of ones' condition, constant worry about relapsing and being judged and experiencing resentment from family members (Hyman, 2008).

In other studies, individuals with OCD often reported feeling mistreated, or even disliked by others (Bhattacharya & Singh, 2015; Helbing & Ficca, 2009; Murphy & Perera-Delcourt, 2014; Storch et al., 2006). For example, individuals with OCD often report having arguments and avoiding affection with a spouse due to their symptoms (Perez, 2008). Furthermore, in a study conducted in the United States, the authors found that 27% of patients reported being maltreated by their friends, which included being mistreated physically (kicking, hitting) and socially (not being accepted by friends) (Storch et al., 2006).

Participants in this study also reported finding it difficult to work with certain colleagues whom they perceive to lack understanding and compassion about their condition. Neal-Barnett and Mendelson (2003) state that one of the main contributions to triggering OCD symptoms in the workplace is the lack of knowledge about the disorder among colleagues, thus resulting in frustration and dissatisfaction with the OCD individual. Therefore, it has been suggested that in the workplace, a good understanding between employer and employee (with OCD) is of significance. Such a relationship assists in acknowledging the rights, individuality and recovery of the person with OCD (Neal-Barnett & Mendelson, 2003).

Families' experience of OCD. Participants in this study perceived their condition as traumatic for their families. Participants reported that family members often became overwhelmed by the responsibility of taking care of them. According to Van Noppen (2006), families often react in extreme and/or conflicting ways towards to the individual with OCD when trying to take care of them. It is clear that the symptoms of the disorder affect the interactions between patients and their family and cause emotional stress, powerlessness, problems, and conflict in the family (Piacentini & Langley, 2004; Stengler-Wenzke et al., 2004).

Exosystem

The underlying theme representative of the exosystem was the impact of OCD on functioning at work and at school.

Impact on work and school.

Decline in school and work attendance. Consistent with other studies (Neal-Barnett & Mendelson, 2003; Tompkins, 2012), several participants reported that their OCD lead to them arriving late, or even prevented them from attending classes, lecturers, meetings, and/or work, often due to time-consuming compulsive rituals such as washing hands or checking something (Paige, 2007). These obsessions and compulsions sometimes make it impossible to complete or take part in activities outside the home (Rees, 1997).

Impact on productivity. Several participants mentioned that OCD affected their school work and career. Neal-Barnett and Mendelson (2003) state that OCD may affect an individual's quality of work, resulting in lower productivity. Obsessions may distract students during classes, while compulsions may inhibit them from partaking in class activities or completing tasks on time, thus having an impact on their academic success (Adams, 2004; French et al., 2009; Purcell, 1999). At times these individuals may obsess about task detail, and spend too much time rewriting (to ensure everything is perfect or that there are no swear words in the text) (Tomkins, 2012), often leading to missed deadlines. On the other hand, several participants in this study also reported positively on the influence of their obsessive-compulsive symptoms on their productivity and quality of work.

Macrosystem

Services. Participants in this study reported positive and supportive interactions with relevant healthcare practitioners. These participants came from middle to high income backgrounds, which differ greatly from the general South African population. Participants reported being able to access and receive services from psychologists, psychiatrists, doctors,

and accessible and helpful support groups. Countless people in the developing world (such as SA) are deprived of adequate healthcare (O'Donnell, 2007). Where healthcare is accessible, the quality is often poor or it is unaffordable to most (O'Donnell, 2007; Thrush & Hyder, 2014), creating a situation of much concern (Karodia & Soni, 2015). In resource-rich countries such as the USA, individuals are more likely to receive the necessary support and assistance to deal with functional impairments (Okpaku, 2014).

In South Africa, 60% of all individuals diagnosed with an anxiety disorder (such as OCD) never see a mental health specialist, so they often consult their family general practitioner, religious leader or a family member for help and support (Rosenstein, 2013). However, the participants of the present study mentioned seeing mental health specialists and being treated with CBT and pharmacotherapy. Furthermore, CBT and SSRIs are safe and effective first-line treatments for OCD (Stein, 2013).

South Africa's health system involves a small, but fast growing private sector and a large public sector. These systems depend greatly on the country's infrastructure and human resources. However, a shortage in some of the human resources remains (Berger et al., 2011). Here, healthcare ranges from the advanced healthcare services accessible in the private sector to the most basic primary healthcare. Since participants in this study are from middle to high income backgrounds and received accessible healthcare services, they most likely received services from the private sector. The private sector also draws interest from the majority of the country's health professionals (Berger et al., 2011). In the South African health system, there are still major injustices. For example, even though the state funds almost 40% of all expenses on health, the public health sector is under pressure to provide services to almost 80% of the population. Regardless of this, most resources receive attention in the private health sector, which meets the health needs of the remaining 20% of the population (Berger et al., 2011). More specifically, there is only one OCD support group in the Western Cape.

Clinicians specialized in treating OCD are in the minority and mostly practice in private clinics (Rosenstein, 2011). These services are expensive and out of reach for most patients with OCD. It appears, however, that the sample here were of the fortunate few who (whose families) could afford specialized care.

Chronosystem

In the context of this study, the chronosystem entails change, over time, of the experience of living with OCD.

Changing experience of living with OCD.

Terrifying experiences. Participants experienced OCD as disturbing, destructive, and debilitating. OCD is known to be a debilitating condition characterized by disturbing thoughts and obsessions (American Psychiatric Association, 2013). Participants reported constantly shifting between worrying about themselves to worrying about how others may perceive them and their illness. This caused them to experience different emotional reactions such as anxiety, stress, irritation, anger, sadness, discomfort, disgust, and embarrassment about having to live with OCD. According to Carroll, Pantelis, and Harvey (2004) and Wahl (1999), such feelings of anger, dissatisfaction, and hopelessness are common in patients with mental health problems.

Coping strategies. Participants reported various ways of coping and adjusting to their condition over time. Coping refers to “constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person” (Lazarus & Folkman, 1984, p. 141). In a study conducted in the United States, participants reported using more problem-focused coping than emotion-focused coping when faced with stressful situations (Hartley, 2007). The current findings do not support the notion that problem-focused coping is used more than emotion-focused coping (Hartley, 2007). Participants reported shifting from first attempting to solve OCD

itself (problem-focused coping) to attempting to solve the emotions associated with their OCD (emotion-focused coping). Participants stated that a change to their person or environment has to be modified by changing their thoughts and feelings about their condition. Consistent with other mental illness studies, participants therefore focus more on using emotion-focused coping in stressful situation (Lee & Schepp, 2011; Souza et al., 2007). Problem-focused coping and emotion-focused coping may, however, be used concurrently or interchangeably (Tuncay et al., 2008). As participants shift from problem-focused coping to emotion-focused coping, they change their thoughts and the way they view their disorder and therefore move towards feelings of acceptance, i.e. accepting their condition and wanting to be accepted by others. The shift from problem-focused coping to emotion-focused coping may imply a step in the direction of accepting everyday problems (Earle et al., 2005). Furthermore, the result of this coping process is seen as an adjustment (Tuncay et al., 2008).

Experience of self with OCD.

Self-esteem. Participants in this study reported a low self-esteem. Several studies have reported that having OCD often leads to individuals experiencing a sense of personal failure, becoming dissatisfied with their inability to cope with and be 'normal', subsequently decreasing their self-esteem and increasing their feelings of guilt (Mancini et al., 2007; Murphy & Delcourt, 2014; Shafran et al., 1996). This experience of a sense of failure is often overwhelming (Bhattacharya & Singh, 2015; Crisp et al., 2005). As a result, individuals may feel hopeless and powerless, because they cannot live up to particular expectations, consequently decreasing their self-esteem (Bhattacharya & Singh, 2015). The findings of this current study are consistent with this as participants reported that their OCD fosters a lack of self-esteem. They saw themselves as weak, imperfect, and considered their lives as almost unbearable. Fennell and Liberato (2007) further support this with their term 'crisis of the self' in OCD (p. 315). According to Ferrier and Brewin (2005), individuals with OCD often make

negative judgements about themselves. Similarly, other studies have found that these individuals are often afraid of what their symptoms may show of their character (Rachman, 1997). Findings of this study show that participants constantly feel self-conscious and are concerned with others' attitudes towards them. Evidence suggests that OCD often results in a lack of self-confidence, self-doubt, and distrust of self (Aardema & O'Connor, 2007).

Self-efficacy. As a result of participants' low self-esteem, their beliefs in their ability to accomplish things or to get things done were also inhibited by their OCD. These participants believed that they were less able to accomplish certain activities and tasks than individuals without OCD. Evidence suggests that the thoughts of OCD sufferers are inherently uncontrollable and they therefore achieve little sense of control and belief in their ability to succeed (self-efficacy), which results in increased anxiety (Bandura & Wood, 1989). According to McClure (2014), individuals may feel trapped and anxious when they cannot control their obsessions and compulsions.

Limitations and Recommendations

This study has several limitations. First, the sample included in this study is not representative of the South African population. Most of the participants included were from middle to high income backgrounds compared to the general population. Future research should include a sample from various socio-economic statuses across South Africa as SES may have an impact on, for example, support systems (i.e. family / environment / healthcare access and affordability).

Second, although the aim was to elicit individual experiences of the impact of OCD daily functioning and QOL, it would have been hugely beneficial to understand the impact on family from the perspectives of family members themselves. Future research should aim to include family members in order to understand their direct experiences of living with someone with OCD.

Third, positive factors (such as positivity about OCD and work, and a boost in self-esteem and self-efficacy) were not commonly described by participants. This is not to say that these factors were not important to the individuals' experience of living with OCD. It is likely that participants were reluctant to share positive experiences given the interview context and the nature of the questioning. As such, participants may have interpreted the interview as one solely focused on the debilitating experiences of their OCD. Therefore, future research is recommended to explore the discursive interpretations of their experiences.

Fourth, interviews were short and once off, thus providing little opportunity for rapport building between the interviewer and the interviewee. Factors influencing the duration of interviews included the anxiousness of some participants and the fact that older participants (ages 52-69) were often unable to articulate the past due to an inability to remember or to concentrate for prolonged periods of time. My age, gender, and being a stranger could have also influenced participants' openness to reveal information. Follow-up interviews may have provided an opportunity for participants to feel sufficiently more comfortable to provide more in-depth information.

Fifth, given the time constraints of the study, the data obtained were not confirmed by the participants. Participant verification entails sending the transcripts or themes emergent from thematic analysis to participants to verify that their experiences were authentically interpreted by the interviews. Therefore, it is recommended that in order to contribute significantly to the credibility of the results, future research apply this method of verifying data.

Furthermore, the information collected from participants will likely assist mental health clinicians in adjusting their strategies to improve treatments and services when dealing with individuals with mental disorders, particularly individuals living with OCD. This study may benefit patients with OCD by providing them with a better understanding and allowing

them to gain greater insight into their own experiences and those of others. This will also allow significant others, such as family members and friends, to better understand the condition. Furthermore, this information may contribute to the scarce information regarding provision and current service resources.

Conclusion

The findings of this study give us insight into how OCD influenced individuals' daily functioning and QOL. The findings showed that participants' experience of their condition was influenced and shaped by their interactions with their family, friends, and colleagues, and their academic performance and work activities, as well as their interaction with their healthcare services, and how they have understood and experienced living with OCD over-time. All of the participants experience OCD as a chronic condition. However, many of them are functional in society (i.e. had jobs or were married). It is clear that while they lived with OCD, they sometimes felt isolated and misunderstood even among loved ones, and were uncertain of how society would act in response to their diagnosis. Although most participants reported poor QOL and daily functioning due to OCD, over time some received support from family and significant others and found ways to cope with their condition, allowing them to reach acceptance.

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APPENDICES

Appendix A: Diagnostic Criteria for Obsessive Compulsive Disorder

A. Presence of either obsessions or compulsions

Obsessions are defined by:

1. Recurrent and persistent thoughts, impulses, or images that are experienced at some time during the disturbance as intrusive and inappropriate and that cause marked anxiety or distress
2. The thoughts, impulses, or images are not simply excessive worries about real-life problems
3. The person attempts to ignore or suppress such thoughts, impulses, or images, or to neutralize them with some other thought or action
4. The person recognizes that the obsessional thoughts, impulses, or images are a product of his or her own mind (not imposed from without as in thought insertion)

Compulsions are defined by:

1. Repetitive behaviors (e.g., hand-washing, ordering, checking) or mental acts (e.g., praying, counting, repeating words silently) that the person feels driven to perform in response to an obsession, or according to rules that must be applied rigidly
2. The behaviors or mental acts are aimed at preventing or reducing distress or preventing some dreaded event or situation; however, these behaviors or mental acts either are not connected in a realistic way with what they are designed to neutralize or prevent or are clearly excessive

B. At some point during the course of the disorder, the person has recognized that the obsessions or compulsions are excessive or unreasonable. Note: This does not apply to children.

C. The obsessions or compulsions cause marked distress, are time consuming (take >1 h/d), or significantly interfere with the person's normal routine, occupational (or academic) functioning, or usual social activities or relationships.

D. If another Axis I disorder is present, the content of the obsessions or compulsions is not restricted to it (e.g., preoccupation with food in the presence of an Eating Disorder; hair pulling in the presence of Trichotillomania; concern with appearance in the presence of Body Dysmorphic Disorder; preoccupation with drugs in the presence of a Substance Use Disorder; preoccupation with having a serious illness in the presence of Hypochondriasis; preoccupation with sexual urges or fantasies in the presence of a Paraphilia; or guilty ruminations in the presence of Major Depressive Disorder).

E. The disturbance is not due to the direct physiological effects of a substance (e.g., a drug of abuse, a medication) or a general medical condition.

(American Psychiatric Association, 2000)

Appendix B: Demographic questionnaire and Self-report measure

CODE			
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DATE			
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Demographic questionnaire & Self-report measure

Date: _____

Please answer the questions below:

Participant name and surname: _____

Participant age: _____

Participant date of birth: / /

 Day Month Year

Participant phone no: _____

Participant email: _____

Participant first language _____

Interviewer name: _____

Interviewer phone no: _____

Start time: _____

End time: _____

Tick the answer that best suit you with an X

Gender

- Male
- Female

Marital status

- Single
- In a relationship but not married
- Married
- Divorced
- Other _____

Living situation:

- ☐ Live alone
- ☐ Live with other adults(s), no children
- ☐ Live with other adults and children
- ☐ Live with children
- ☐ Live in an institution or retirement home

What is the highest education level you have completed?

- ☐ No formal education
- ☐ Completed primary school
- ☐ Attended high school but did not complete matric
- ☐ Completed matric
- ☐ Attended university, college or technikon but did not graduate
- ☐ Graduated from university, college or technikon

What is your current work situation?

- ☐ Employed full time
- ☐ Employed part time
- ☐ Student
- ☐ Unemployed
- ☐ Disabled
- ☐ Homemaker
- ☐ Retired

Which of the following best describes your approximate monthly family income from all sources, before taxes?

- ☐ Less than R2500
- ☐ R2 501-R5 000
- ☐ R5 001-R10 000
- ☐ R10 001 – R15 000
- ☐ R15 001 and above
- ☐ Don't know

Onset of Obsessive-Compulsive Symptoms

- ☐ Under 12 years old
- ☐ 12-17 years old
- ☐ 18-24 years old
- ☐ 25-34 years old
- ☐ 35-44 years old
- ☐ 45-54 years old
- ☐ 55-64 years old
- ☐ 65-74 years old
- ☐ 75 years or older

Onset of Obsessive-Compulsive Disorder

- ☐ Under 12 years old
- ☐ 12-17 years old
- ☐ 18-24 years old
- ☐ 25-34 years old
- ☐ 35-44 years old
- ☐ 45-54 years old
- ☐ 55-64 years old
- ☐ 65-74 years old
- ☐ 75 years or older

Are you receiving any medications or treatments?

☐ Yes☐ No

If yes, please provide a description.

Based on your evaluation, you have symptoms of obsessive-compulsive disorder. I would like to better understand how much of a problem these symptoms are. Please answer the following five questions for the following symptoms over the past 7 days:

1. **Obsessions** (unwanted thoughts, urges, or images that repeatedly enter your mind (for example, concerns with contamination, with terrible things happening, with keeping objects in perfect order or arranged exactly, or personally unacceptable religious or sexual thoughts)

AND

2. **Compulsions** (feeling driven to perform certain behaviours or mental acts over and over again (for example, excessive or ritualised washing or cleaning; repeatedly checking or asking for reassurance; counting, arranging, or making things even or right)

Tick the box next to the most appropriate number from 0 to 4 with an X.

On average, how much <i>time</i> is occupied by these symptoms?	0 None	1 Mild (less than 1 hour)	2 Moderate (1 to 3 hours)	3 Severe (3 to 8 hours)	4 Extreme (more than 8 hours)
How much <i>distress</i> do they cause you?	0 None	1 Mild	2 Moderate	3 Severe	4 Extreme (disabling)
How hard is it for you to <i>control</i> them?	0 Complete control	1 Much control	2 Moderate control	3 Little control	4 No control
How much do they cause you to <i>avoid</i> doing anything, going anyplace, or being with anyone?	0 No avoidance	1 Occasional avoidance	2 Moderate avoidance	3 Frequent and extensive avoidance	4 Extreme avoidance (housebound)
How much do they <i>interfere</i> with school, work, or your social or family life?	0 None	1 Slight interference	2 Moderate; definitely interferes with functioning	3 Much interference	4 Extreme interference (disabling)

Appendix C: English interview schedule**Interview schedule****Introduction questions**

Describe your earliest recollection/memory/experience of OCD.

Probe: When did you start realising that your OCD symptoms (behaviours or thoughts) were too much for you to handle?

Daily activity experiences

Describe a good day.

What sorts of things do you enjoy doing?

To what extent do your obsessions and/or compulsions prevent you from doing these things?

Probe: Do you remember a specific day where your obsessions and/or compulsions prevented you from going somewhere or doing something with someone? Can you tell me about that?

What was it like?

Probe: How satisfied are you with your ability to do things while living with OCD?

Probe: To what extent do your obsessions and/or compulsions allow you the opportunity for leisure activities?

Quality of life in the immediate environment

How do you think your family has experienced your diagnosis?

Probe: Your parents during your childhood, your brothers or sisters, your husband or wife, your children?

How do you think OCD has influenced your social relationships?

Probe: Your friends, forming of new relationships.

How do you think OCD has influenced your academic or work performance?

Has OCD affected your self-esteem /i.e. the way you see and value yourself? If so, how?

Concluding questions:

Do you have anything to add on your quality of life, living with OCD?

Describe your experience of this interview?

Appendix D: Afrikaans interview schedule**Onderhouds vraelys****Inleidende vrae**

Beskryf jou eerste herinnering/ eerste ervaring van OKV.

Ondersoekende vraag: Wanneer het jy begin besef dat jou OKV simptome (gedrag of denke) te veel was vir jou om te hanteer ?

Daaglikse aktiwiteite

Beskryf 'n goeie dag as dinge gaan soos dit moet.

Watter soort dinge geniet jy om te doen?

Tot watter mate verhoed jou obsessies en kompulsies om hierdie dinge te doen?

Ondersoekende vraag: Onthou jy 'n spesifieke dag waar jou obsessies en/of kompulsies jou verhoed het om iewers uit te gaan of iets te doen met iemand? Kan jy my oor dit vertel? Hoe was dit?

Ondersoekende vraag: Hoe bevredig is jy met jou vermoëns om dinge te doen terwyl jy lewe met OKV?

Ondersoekende vraag: Tot watter mate laat die obsessies en kompulsies jou toe om deel te neem aan ontspanningsaktiwiteite?

Lewensgehalte binne die omgewing.

Hoe dink jy ervaar jou gesin die diagnose?

Ondersoekende vraag: Jou ouers, jou broers or susters, jou man of vrou, jou kinders?

Hoe dink jy het OKV jou verhoudinge met ander beïnvloed?

Ondersoekende vraag: Jou vriende, vorming van nuwe verhoudings.

Hoe dink jy het OKV jou akademiese of werkprestasie beïnvloed?

Dink jy dat OKV 'n impak het op jou eiewaarde met ander woorde hoe jy oor jouself voel en die waarde wat jy aan jouself heg? Indien so, in watter mate?

Afsluiting vrae

Het jy nog iets om by te voeg op jou lewensgehalte van 'n lewe met OKV?

Beskryf jou ervaring van hierdie onderhoud?

Appendix E: English consent form**PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM**

TITLE OF THE RESEARCH PROJECT: Delineating Endophenotypes of Obsessive-Compulsive Disorder (OCD) and Hair-Pulling Disorder (Trichotillomania [TTM]): An Integrated Pharmacological, Neurocognitive, Genetic and Imaging Study

TITLE OF SUBSTUDY: Obsessions and compulsions- A qualitative inquiry into the lives of individuals living with obsessive-compulsive disorder (OCD).

REFERENCE NUMBER: M07/05/019

PRINCIPAL INVESTIGATOR: Prof Christine Lochner

SUB-INVESTIGATORS: Dr Bronwyne Coetzee; Ms Kirsten Kohler

ADDRESS: Faculty of Medicine and Health Sciences, Tygerberg campus, Stellenbosch University

CONTACT NUMBER: Prof C Lochner (021 938 9179), Dr B Coetzee (021 808 3979), Ms K Kohler (0605091893)

You are being invited to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask the study staff or doctor any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part.

This study has been approved by the **Health Research Ethics Committee at Stellenbosch University** and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

What is this research study all about?

- *With this research we hope to understand the ways in which OCD influences daily functioning and quality of life among individuals (18 years old or older) living with OCD. More specifically, we would like to explore the impact of OCD on family functioning, social activities, academic and work performance, and on self-esteem.*
- *We would like to invite up to 20 individuals with OCD to take part in interviews.*
- *If you consent to take part, you will be asked to complete two questionnaires before the start of the interview.*
- *The interview will last no longer than 90 minutes. We will arrange for the interview to take place at your convenience, either at the SU/UCT MRC Unit on Anxiety and Stress Disorders or telephonically, or via Skype.*
- *The interview will consist of semi-structured questions.*
- *The interviews will be conducted by one or two of the investigating researchers and will be audio recorded.*
- *This research project is for degree purposes (MA in Research Psychology).*

Why have you been invited to participate?

- *You have been invited to participate in this study, as you are 18 years old or older and have been diagnosed with OCD.*

What will your responsibilities be?

- *You are required to read the consent form thoroughly and ask the researcher any questions you may have to further clarify the information.*
- *You should understand the process of the study before you agree to participate.*
- *Take note of possible benefits and risks of participating in the study.*

- *Fulfil the responsibilities of participation as described in the consent forms.*
- *Tell the researcher if you no longer wish to participate. There will be no consequence for your withdrawal.*
- *Contact the researcher with any problems or concerns regarding the study or your participation in the study.*
- *Keep a copy of the consent form.*

Will you benefit from taking part in this research?

- *You will not benefit financially from participation, but transport costs will be covered. This study will contribute to the limited knowledge on experiences of living with OCD amongst individuals in South Africa. This study is likely to benefit OCD patients (those participating in the study and future patients) by providing them with a better understanding of and allowing them to gain greater insight into their own experiences and those of others.*
- *Referrals for treatment can be made, if required.*

Are there any risks involved in taking part in this research?

- *There are medium psychological risks associated with this study. If you feel fatigued, uncomfortable, or in any way upset during any part of the session, you may ask to stop for a rest break or have the interview discontinued.*
- *The research interview does not take the place of a full psychiatric evaluation. You may experience some emotional discomfort when answering some questions.*
- *If any particular question makes you feel uncomfortable, you may discuss its importance with the specially trained interviewer. You may choose not to answer any question should you feel uncomfortable.*

If you do not agree to take part, what alternatives do you have?

- *Your participation is entirely voluntary. You can choose to not take part without consequence.*

Who will have access to your medical records?

- *We will not be accessing your medical records.*

Will you be paid to take part in this study and are there any costs involved?

- *You will not be paid to take part in the study but your transport costs will be covered, if requested (to a maximum of R150).*

Is there anything else that you should know or do?

- *You can contact Prof C Lochner (0219389179) or Dr B Coetzee (021 808 3979) if you have any further queries or encounter any problems.*
- *You can contact the Health Research Ethics Committee at 021-938 9207 if you have any concerns or complaints that have not been adequately addressed by your study doctor.*
- *You will receive a copy of this information and consent form for your own records.*

Declaration by participant

By signing below, I agree to take part in a research study entitled *Delineating Endophenotypes of Obsessive-Compulsive Disorder (OCD) and Hair-Pulling Disorder (Trichotillomania [TTM]): An Integrated Pharmacological, Neurocognitive, Genetic and Imaging Study AND substudy entitled: Obsessions and compulsions- A qualitative inquiry into the lives of individuals living with obsessive-compulsive disorder (OCD).*

I declare that:

- I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.
- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.

- I may be asked to leave the study before it has finished, if the study doctor or researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

Signed at (*place*) on (*date*)..... 2016.

.....
Signature of participant

.....
Signature of witness

Declaration by investigator

I (*name*) declare that:

- I explained the information in this document to
.....
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above
- I did/did not use an interpreter. (*If an interpreter is used then the interpreter must sign the declaration below.*)

Signed at (*place*) on (*date*)..... 2016.

.....
Signature of investigator

.....
Signature of witness

Declaration by interpreter

I (*name*) declare that:

- I assisted the investigator (*name*) to explain the information in this document to (*name of participant*) using the language medium of Afrikaans/Xhosa.

- We encouraged him/her to ask questions and took adequate time to answer them.
- I conveyed a factually correct version of what was related to me.
- I am satisfied that the participant fully understands the content of this informed consent document and has had all his/her question satisfactorily answered.

Signed at (*place*) on (*date*)..... 2016.

.....
Signature of interpreter

.....
Signature of witness

Appendix F: Afrikaans consent form**DEELNEMERINLIGTINGSBLAD EN -TOESTEMMINGSVORM**

TITEL VAN DIE NAVORSINGSPROJEK: Delineating Endophenotypes of Obsessive-Compulsive Disorder (OCD) and Hair-Pulling Disorder (Trichotillomania [TTM]): An Integrated Pharmacological, Neurocognitive, Genetic and Imaging Study

TITEL VAN SUB-STUDIE: Obsessions and compulsions- A qualitative inquiry into the lives of individuals living with obsessive-compulsive disorder (OCD).

VERWYSINGSNOMMER: M07/05/019

HOOFNAVORSER: Prof Christine Lochner

SUB-ONDERSOEK NAVORSERS: Dr Bronwyne Coetzee; Ms Kirsten Kohler

ADRES: Fakulteit van Medisyne en Gesondheidswetenskappe, Tygerberg Kampus, Stellenbosch Universiteit

KONTAKNOMMER: Prof C Lochner (021 938 9179), Dr B Coetzee (021 808 3979), Ms K Kohler (0605091893)

U word genooi om deel te neem aan 'n navorsingsprojek. Lees asseblief hierdie inligtingsblad op u tyd deur aangesien die detail van die navorsingsprojek daarin verduidelik word. Indien daar enige deel van die navorsingsprojek is wat u nie ten volle verstaan nie, is u welkom om die navorsingspersoneel of dokter daaroor uit te vra. Dit is baie belangrik dat u ten volle moet verstaan wat die navorsingsprojek behels en hoe u daarby betrokke kan wees. U deelname is ook **volkome vrywillig** en dit staan u vry om deelname te weier. U sal op geen wyse hoegenaamd negatief beïnvloed word indien u sou weier om deel te neem nie. U mag ook te eniger tyd aan die navorsingsprojek onttrek, selfs al het u ingestem om deel te neem.

Hierdie navorsingsprojek is deur die Gesondheidsnavorsingsetiekkomitee (GNEK) van die Universiteit Stellenbosch **goedgekeur en sal uitgevoer word volgens die etiese riglyne en beginsels van die Internasionale Verklaring van Helsinki en die Etiese Riglyne vir Navorsing van die Mediese Navorsingsraad (MNR).**

Wat behels hierdie navorsingsprojek?

- *Met hierdie navorsing hoop ons om die wyse waarop OKS daaglikse funksionering en lewenskwaliteit, in individue (18 jaar oud of ouer) met OKS, beter te verstaan. Meer spesifiek, wil ons graag die impak van OKS op gesinsfunksionering, sosiale aktiwiteite, akademiese en werkprestasie, en op selfbeeld te verken.*
- *Ons wil graag 20 individue met OKS nooi om deel te neem in onderhoude.*
- *As jy instem om deel te neem, sal jy gevra word om twee vraelyste te voltooi voor die aanvang van die onderhoud.*
- *Die onderhoud sal nie langer as 90 minute duur nie. Ons sal reël dat die onderhoud op jou gemak plaasvind, óf by die US / UCT MNR Eenheid vir Angs en Stressteurings of telefonies, of via Skype.*
- *Die onderhoud sal bestaan uit semi-gestruktureerde vrae.*
- *Die onderhoude sal deur een of twee van die ondersoekende navorsers gedoen word en daar sal ook 'n bandopname van die onderhoud gemaak word.*
- *Hierdie navorsingsprojek is vir graaddoeleindes (MA in Navorsingsielkunde).*

Waarom is u genooi om deel te neem?

- *Jy is uitgenooi om deel te neem aan hierdie studie , omdat jy 18 jaar oud of ouer is en gediagnoseer is met OKS .*

Wat sal u verantwoordelikhede wees?

- *Jy word versoek om die toestemmingsvorm deeglik te lees en vir die navorser te vra om die inligting verder te verduidelik as dit nodig is.*
- *Jy moet die proses van die studie verstaan voordat jy saamstem om deel te neem.*
- *Let op die moontlike voordele en risiko's van deelname aan die studie.*

- *Voltooi die verantwoordelikheid van deelname soos beskryf word in die toestemmingsvorms.*
- *Vertel die navorser as jy nie meer wil deelneem nie. Daar sal geen gevolge vir jou onttrekking wees nie.*
- *Kontak die navorser met enige probleme of bekommernisse met betrekking tot die studie of jou deelname aan die studie.*
- *Hou 'n afskrif van die toestemmingsbrief.*

Sal u voordeel trek deur deel te neem aan hierdie navorsingsprojek?

- *Jy sal nie finansieel voordeel trek uit deelname nie, maar vervoerkoste sal gedek word . Hierdie studie sal bydra tot die beperkte kennis oor OKS ervarings in individue met OKS in Suid-Afrika. Hierdie studie is geneig om OKS pasiënte (diegene wat deelneem aan die studie en toekomstige pasiënte) te baat deur hulle 'n beter begrip van en groter insig in hul eie ervarings en dié van ander te gee.*
- *Verwysings vir behandeling kan gedoen word, indien nodig .*

Is daar enige risiko's verbonde aan u deelname aan hierdie navorsingsprojek?

- *Daar is medium sielkundige risiko's wat verband hou met hierdie studie. As jy moeg, ongemaklik of ontsteld voel tydens enige deel van die sessie kan jy vra om op te hou vir 'n ruskans of die onderhoud eindig.*
- *Die navorsingsonderhoud neem nie die plek van 'n volledige psigiatriese evaluering nie. Jy mag dalk emosionele ongemak ervaar tydens die beantwoording van 'n paar vrae.*
- *As 'n bepaalde vraag jou ongemaklik laat voel , kan jy die belangrikheid daarvan met die opgeleide onderhoudvoerder bespreek. Jy kan kies om enige vraag wat jou laat ongemaklik voel nie te antwoord nie.*

Watter alternatiewe is daar indien u nie instem om deel te neem nie?

- *U deelname is heeltemal vrywillig. Jy kan sonder gevolg kies om nie deel te neem nie.*

Wie sal toegang hê tot u mediese rekords?

- *Ons sal nie toegang tot jou mediese rekords hê nie.*

Sal u betaal word vir deelname aan die navorsingsprojek en is daar enige koste verbonde aan deelname?

- *Jy sal nie betaal word om deel te neem in die studie nie, maar jou vervoerkoste sal gedek word, indien versoek (tot 'n maksimum van R150) .*

Is daar enigiets anders wat u moet weet of doen?

- *Jy kan Prof C Lochner (0219389179) of Dr B Coetzee (021 808 3979) kontak indien u enige verdere navrae of probleme ondervind .*
- *Jy kan by 021-938 9207 die Gesondheid Navorsingsetiekkomitee kontak as jy enige probleme ondervind of klagtes wat reeds nie voldoende deur jou studie dokter aanspreek .*
- *Jy sal 'n afskrif van hierdie inligting en toestemmingsvorm ontvang vir u eie rekords.*

Verklaring deur deelnemer

*Met die ondertekening van hierdie dokument onderneem ek,, om deel te neem aan 'n navorsingsprojek getiteld **Delineating Endophenotypes of Obsessive-Compulsive Disorder (OCD) and Hair-Pulling Disorder (Trichotillomania [TTM]): An Integrated Pharmacological, Neurocognitive, Genetic and Imaging Study** en sub-studie getiteld: **Obsessions and compulsions- A qualitative inquiry into the lives of individuals living with obsessive-compulsive disorder (OCD).***

Ek verklaar dat:

- Ek hierdie inligtings- en toestemmingsvorm gelees het of aan my laat voorlees het en dat dit in 'n taal geskryf is waarin ek vaardig en gemaklik mee is.
- Ek geleentheid gehad het om vrae te stel en dat al my vrae bevredigend beantwoord is.
- Ek verstaan dat deelname aan hierdie navorsingsprojek **vrywillig** is en dat daar geen druk op my geplaas is om deel te neem nie.
- Ek te eniger tyd aan die navorsingsprojek mag onttrek en dat ek nie op enige wyse daardeur benadeel sal word nie.

- Ek gevra mag word om van die navorsingsprojek te onttrek voordat dit afgehandel is indien die studiedokter of navorser van oordeel is dat dit in my beste belang is, of indien ek nie die ooreengekome navorsingsplan volg nie.

Geteken te (plek) op (datum)
2016.

.....
Handtekening van deelnemer

.....
Handtekening van getuie

Verklaring deur navorser

Ek (naam) verklaar dat:

- Ek die inligting in hierdie dokument verduidelik het aan
- Ek hom/haar aangemoedig het om vrae te vra en voldoende tyd gebruik het om dit te beantwoord.
- Ek tevrede is dat hy/sy al die aspekte van die navorsingsprojek soos hierbo bespreek, voldoende verstaan.
- Ek 'n tolk gebruik het/nie 'n tolk gebruik het nie. (*Indien 'n tolk gebruik is, moet die tolk die onderstaande verklaring teken.*)

Geteken te (plek) op (datum)
2016.

.....
Handtekening van navorder

.....
Handtekening van getuie

Verklaring deur tolk

Ek (*naam*) verklaar dat:

- Ek die navorser (*naam*) bygestaan het om die inligting in hierdie dokument in Afrikaans/Xhosa aan (*naam van deelnemer*) te verduidelik.
- Ons hom/haar aangemoedig het om vrae te vra en voldoende tyd gebruik het om dit te beantwoord.
- Ek 'n feitelik korrekte weergawe oorgedra het van wat aan my vertel is.
- Ek tevrede is dat die deelnemer die inhoud van hierdie dokument ten volle verstaan en dat al sy/haar vrae bevredigend beantwoord is.

Geteken te (*plek*) op (*datum*)
2016.

.....
Handtekening van tolk

.....
Handtekening van getuie

Appendix G: Invitation to participate

My name is Kirsten Kohler. I am a Masters student from the Department of Psychology/Psychiatry at Stellenbosch University. Professor Christine Lochner has let me know that you have agreed to participate in my study and that it is okay for me to contact you regarding this study. Below is a brief description of my study.

Title of study: Obsessions and compulsions- A qualitative inquiry into the lives of individuals living with obsessive-compulsive disorder (OCD).

What is this research study all about? With this research we hope to understand the ways in which OCD influences daily functioning and quality of life among individuals (18 years old or older) living with OCD. More specifically, we would like to explore the impact of OCD on family functioning, social activities, academic and work performance, and on self-esteem. If you consent to take part, you will be asked to complete two questionnaires before the start of the interview. The interview will last between 1hour-1h30min. We will arrange for the interview to take place at your convenience, either at the SU/UCT MRC Unit on Anxiety and Stress Disorders or telephonically, or via Skype. Your participation is entirely voluntary and you can withdraw at any time of the study without consequence. You will be provided with a travel voucher as a token of appreciation for your participation and time in the study.

If you would like more information about the research, please contact me. We look forward to your involvement.

Appendix H: Ethics letter for current study



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Ethics Letter

26-Apr-2016

Ethics Reference #: M07/05/019

Clinical Trial Reference #:

Title: "Delineating endophenotypes of obsessive-compulsive disorder: An integrated pharmacological, neurocognitive, genetic and imaging study."

Dear Prof Christine Lochner,

The HREC approved the following documentation pertaining to the abovementioned trial:

- Protocol Amendment dated 24 February 2016
- Demographic Questionnaire and Interview Schedule
- Participant Information Leaflet and Consent Form

If you have any queries or need further assistance, please contact the HREC Office 0219389657.

Sincerely,

REC Coordinator
Franklin Weber
Health Research Ethics Committee 1

Appendix I: Ethics letter for broader study

